Facilitators and barriers to status disclosure and partner testing of women living with HIV in Indonesia: a mixed methods study

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Facilitators and barriers to status disclosure and partner testing of women living with HIV in Indonesia: a mixed methods study

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Abstract: This mixed-methods study investigated HIV status disclosure and partner testing of women living with HIV (WLWH) in a concentrated epidemic setting in Bandung, Indonesia. The qualitative exploratory strand used theoretical sampling to carry out semi-structured interviews with 47 HIV-infected women with varying anti-retroviral therapy status. The quantitative strand included 122 female patients receiving HIV care at a referral clinic. HIV diagnosis made women reassess their sexual partnerships. Some lost their partner due to death or divorce. Women with a longstanding HIV infection often formed new partnerships. They disclosed their status to new partners without assistance from health providers; the type and stability of the partnership influenced decision to disclose. Fear of rejection prevented initial disclosure prior to bringing the new partners to a health provider. Disclosure did not always result in partner testing because of low risk-awareness or denial of the partner. Despite a similar proportion of status disclosure to partner (92.8%), only 53.7% of new partners of WLWH were tested in contrast to 89.7% of partners tested among WLWH who stayed with the same partner. In antenatal care, where same-day testing was often done for pregnant couples, more partners were tested. Overall, consistent condom use was low and HIV status forced WLWH who continued sex work to work at settings where condom use was not enforced. WLWH face barriers to HIV status disclosure and partner testing and would benefit from partnership counselling. Guidelines for partner notification and testing should include specific strategies for women with longstanding HIV infection. DOI: 10.1080/26410397.2022.2028971

Keywords: HIV status disclosure, HIV partner testing, partner notification, long-term HIV, women living with HIV

Introduction

To increase the number of people tested for HIV, WHO issued a guideline on assisted partner notification services, involving tracing and offering HIV testing to partners of people living with HIV (PLWH). Health providers’ assistance played a role in successful partner notification and testing. Passive partner notification, i.e. when PLWH are expected to disclose their status to sexual partners without the active involvement of health providers, resulted in low numbers of partners tested. Assisted partner notification services, i.e. with active involvement of health providers, resulted in a higher number of partners tested and better linkage to treatment for HIV-positive partners. Assisted partner notification has been implemented in many settings, such as sub-Saharan Africa and other areas with concentrated epidemics. Outside of sub-Saharan Africa, HIV transmission is more heterogeneous with around
80% of new HIV cases concentrated in specific at-risk populations and their sexual partners, making partner testing a strategic approach in HIV case finding and prevention.10

In the era before combination antiretroviral therapy (ART) was widely available, an HIV diagnosis tended to lower the number of sex partners that an individual had.11 As the widespread availability of ART increased life expectancy of PLWH, more PLWH with a longstanding infection resumed sexual activity in existing or new relationships, suggesting a potential need for partner testing in new sexual partnerships, even long after the initial HIV diagnosis.12 Increasing new sexual partnerships, often combined with reduced preventive behaviour, has been recorded in PLWH taking antiretroviral therapy (ART) for ≥4 years.13 Status disclosure to new sexual partners can be challenging for PLWH with a longstanding infection.14 Status disclosure and partner notification for PLWH with a longstanding infection requires different counselling approaches than for newly diagnosed PLWH.12,15

In Indonesia, the first wave of HIV epidemics spread mainly from men who inject drugs. Their (mostly female) sexual partners were expected to be the start of the next phase of the epidemics.16,17 A cohort study at the main referral clinic for HIV care found an increased proportion of new female patients between 2007 and 2012 and around 25% were tested because of partner notification from an HIV-positive male partner.18 Status disclosure to sexual partner, however, happened less often from female patients than from male patients; women living with HIV (WLWH) preferred to disclose their status to their mother or other family members.18,19 This gender difference might be partly explained by an association between status disclosure and internalised stigma, due to the intersectionality between health-related stigma and gender in Indonesia.20,21 WLWH faced double stigma as living with HIV meant women were considered either to be promiscuous or to have a bad character, and WLWH who internalised this stigma might be reluctant to disclose their HIV status.

The Indonesian Ministry of Health issued a national policy on partner notification and testing along with the introduction of a test and treat policy in 2018 but until the writing of this paper the technical guidance has yet to be written, even though some healthcare providers have been trained to implement the policy. There are differing preferences on how to communicate partner notification; while healthcare providers and PLWH are reluctant for there to be explicit mention of HIV, there is some evidence that the general population believe the message would otherwise be easy to ignore.22 Previous studies have identified the need for HIV and AIDS policies to encompass interventions for women in the general population; however, HIV care in Indonesia has been focused on key populations (men having sex with men, people who inject drugs, and sex workers) as well as sexual and reproductive health services targeting pregnant WLWH.23 To identify the needs in partner notification services in all WLWH, including those who are not sex workers and not pregnant, we investigated the practices in HIV status disclosure and partner testing of WLWH in an urban setting in Bandung, Indonesia.

Methods

Study site and population

The study was conducted in Bandung, the capital of West Java, the province with the third highest incidence of HIV in Indonesia.24 Bandung City Area is home to 2.5 million people with over 8.5 million living and working around the city.25 It is a thriving, industrialised metropolitan area with high-income segregation and a growing urban slum.26 Most inhabitants reported Sundanese as their ethnicity and Islam as their religion.27

The first HIV testing and treatment service in Bandung was started in the early 2000s at a clinic of the provincial referral hospital.28 Voluntary counselling and testing (VCT) was available as an outreach programme through community-based organisations working with people who inject drugs (PWID), female sex workers (FSW), and men having sex with men (MSM). VCT and additional harm reduction services were later expanded to selected public health centres in areas with known concentration of PWID in the community, after training one staff person for HIV counselling. At the time of this study, antiretroviral therapy (ART) is provided at both the provincial referral hospital and the municipal general hospital, as well as several private hospitals and the above-mentioned public health centres.

Despite the availability of services, a multi-site cohort study on key populations (PWID, FSW, and MSM) in Indonesian major cities, including Bandung, showed low treatment retention and viral
suppression, suggesting an increased risk of transmission to additional sex partners and children.29

Research design
This mixed-method study consisted of an exploratory qualitative strand combined with a second quantitative strand (commonly symbolised as QUAL→quan). In the exploratory study, we collected ethnographic data among WLWH in Bandung, Indonesia to understand their past vulnerability to HIV and their sexual and reproductive health in relation to HIV transmission. Ethnography is understood as a method to produce understanding through richness, texture, and detail.30 More explanation about the research design can be found in our publication about the factors related to women’s vulnerability to HIV.31 This paper presents the findings related to sexual partnerships and partner disclosure of WLWH. Based on the qualitative data, we developed a questionnaire to collect quantitative data on the women’s partnership status, HIV status disclosure to sexual partners, and the frequency of partner testing.

Concept definitions
Women with longstanding HIV infection
To understand the factors driving sexual partnerships of WLWH, we differentiate between newly diagnosed WLWH and women with longstanding HIV infection. In this study we define longstanding HIV infection as an HIV diagnosis ≥2 years before the study period, regardless of the women’s HIV treatment status. The relevance of this distinction for this study lies in the basic assumption that although HIV acceptance and adaptation is a process with varying duration in different individuals, with time HIV diagnosis is increasingly accepted. In the literature, there is no convention on exactly how long following HIV diagnosis an individual is to be considered as having a longstanding infection.32,33

Sexual partnership
We defined sexual partnership as any heterosexual relationship involving sexual intercourse between WLWH and a man, ranging from a husband to a sex work client. Casual sex is included within this definition.

Casual sex
We defined casual sex as sexual intercourse between WLWH and a man who is not their main partner: it could be a sex work client, a short-term boyfriend, or a non-committal sexual partner (a “fuck buddy”). The WLWH who have multiple partners might consider one partner as their “main”, or “regular” partner, but not all WLWH with multiple casual sex encounters have a main partner. In this study, we let each woman decide whether a sex partner is a boyfriend or a client. In most cases, the shift between a client into a boyfriend happened once feelings were involved, the meetings were more frequent, and the woman received non-monetary payment in exchange for sex.

Qualitative strand
Data collection
Between February 2016 and April 2017, we carried out in-depth interviews with WLWH who had different types of partnership status and relationship history and conducted participant observations at sex work venues and midwife clinics that provided HIV testing. To complement the in-depth interviews, as part of the participant observation we had informal conversations with sexual and reproductive health providers to understand actual behaviour related to sexual and reproductive health services. Informal conversations are interviews that are deliberately kept informal (i.e. not recorded or no notes taken during the interview) to put respondents at ease and reduce response bias. They are treated like other interviews for analysis. To mitigate any respondent discomfort, in-depth interviews were not recorded; the interviewer took notes during the interviews and typed a full summary right after the interviews to ensure that all information in the interviews was recorded as far as possible.

Sampling
We recruited WLWH from three different clinics providing HIV treatment, from an NGO providing mobile VCT at sex work venues (i.e. brothels, karaoke bars, and massage parlours), and from two private physician practices that care for HIV patients. Counsellors at the clinics, who had developed trusted relationships with WLWH, assisted in recruitment and aided in facilitating rapport between the researcher and the participants. Initially, we purposively selected women with different marital status (i.e. married, widowed, divorced, or single) and mode of HIV diagnosis (i.e. through having a positive partner, a positive child, symptoms, or antenatal care). Following
the principles of gradual selection, we further recruited women who had not started treatment or dropped out of treatment and those who were diagnosed with HIV at sites that rarely found positive cases, such as tuberculosis clinics and a blood donation centre. Women whose characteristics and experiences are very different from the others were also included to ensure maximum variation. A more extensive explanation of the qualitative data collection and sampling methods has been published elsewhere.31

Data analysis
The qualitative data were analysed in a continuous, flexible, and iterative process, concurrent to data collection. Preliminary results helped us develop hypotheses and theories that were further tested in the field to confirm or refute the results through constant validity checks, until saturation was reached. Raw data were analysed and coded to generate themes for further analysis. Data management and analysis were carried out in RQDA in R (R version 3.3.0, The R Foundation for Statistical Computing) and NVivo 12 Qualitative Data Analysis software (QSR International Pty Ltd. Cardigan, UK). Coding was done both inductively (i.e. generate new theory from data) and deductively (i.e. test an existing theory through observations) for in-depth analysis. For coding, we used themes such as “HIV vulnerability”, “access to reproductive health services”, and “economic disadvantage” as well as emerging themes such as “divorce/widow stigma” and “new partnership decision-making”. The themes related to partnership, status disclosure, and partner testing were used to develop the questionnaire for the survey.

Quantitative strand
Data collection
The questionnaire was based on the qualitative study results related to partnership, status disclosure, and partner testing. Additional questions related to sexual partnership were adapted from the UNAIDS questionnaire for sexual networks.34 The first author administered the questionnaire in interviews that lasted around 30–45 minutes in a private room at the HIV clinic.

Sampling
We conducted the quantitative study at one of the clinics providing HIV treatment where we had also recruited participants for the qualitative study in the preceding year. This clinic is the main HIV referral clinic at the provincial hospital, providing HIV treatment to around 50% of HIV patients in the city. During the time of the study (i.e. the month of July 2018) 471 WLWH received ART from the clinic, with 352 of them (75%) visiting the clinic themselves, while the others had someone else (e.g. partner, outreach worker) collect it for them. In a cohort study at the same clinic, 4% of male partners were tested following partner notification of female patients.18 To measure the prevalence of male partners of female patients following partner notification with 95% confidence interval and ±5% margin of error, the sample size of WLWH with partners needed for this survey would be 60. Our qualitative data indicated that some women disclosed their HIV status to their partners, but the partners did not get tested. We therefore doubled the sample size to 120. The survey was conducted throughout the month of August 2018.

Data analysis
Questionnaire data were entered and cleaned in MS Excel and analysed in R (R version 3.3.0, The R Foundation for Statistical Computing). Descriptive statistics and significance tests were computed to summarise the relationship between women’s characteristics and partner notification and testing, contrasting between WLWH who stayed with the same partner after HIV diagnosis and those who formed new partnerships.

Ethical considerations
The study protocol was approved on 11 February 2016 by the Health Research Ethics Committee of the Faculty of Medicine Padjadjaran University in Bandung, Indonesia No. 143/UN6.C1.3.2/KEPK/PN/2016. All participants received information before study participation about the objectives of the study, the topic and types of questions, and the intended use of results for scientific publications. They were informed of the right to decline the interview or to withdraw any information during or after the interview. In the qualitative study, written or oral consent was given depending on the circumstances of the interview (formal interviews were documented with written consent, informal conversation relied on oral consent). Oral consent was documented by the first author on paper with the presence of a witness, in this case the witness was the counsellor who assisted in recruitment of study participants. In the quantitative survey, the doctor at the HIV clinic assisted in recruitment of study participants. In the qualitative study, written or oral consent was given depending on the circumstances of the interview (formal interviews were documented with written consent, informal conversation relied on oral consent). Oral consent was documented by the first author on paper with the presence of a witness, in this case the witness was the counsellor who assisted in recruitment of study participants. In the quantitative survey, the doctor at the HIV clinic assisted in recruitment of study participants.
clinic explained the information about the objectives of the study, the topic and types of questions, and the intended use of results for scientific publications, when patients came for their monthly follow-up at the HIV clinic. Then patients who agreed to participate were invited to another private room to be interviewed by the researcher. The researcher repeated the information, explained the right to decline the interview or to withdraw any information during or after the interview, and that declining to take part in the study would not affect the treatment received at the clinic. Written consent was given by all quantitative survey participants. To ensure confidentiality of the study participants, we assigned pseudonyms during qualitative analysis and used a code to identify participants in the quantitative survey. We also removed any mention of exact names of places. While we did not change the age of participants, the data collection was conducted over a period of two years and we did not specify exactly the year of interview of each participant.

Results

Study participants

In the qualitative strand, data saturation was reached after in-depth interviews with 47 WLWH aged 18–42 years old. Fifteen of them had a history of sex work. The length of time they had lived with HIV varied from one month to over ten years. Their ART status varied: most were on ART, some had not initiated treatment, a few had dropped out or had not restarted ART after receiving it as part of PMTCT (before Indonesia adopted the universal lifelong ART for pregnant and breastfeeding women known as “Option B+”). Those on ART were regular clients at one of three main ART facilities in the city. One WLWH was also interviewed in the quantitative strand.

In the quantitative strand, of 128 female clients approached for an interview, 122 agreed (response rate 95%). The median age was 35 (interquartile range [IQR] = 30–38.75). Their sociodemographic characteristics were similar to the qualitative study participants (Table 1). The women were regular clients at the HIV clinic, attending for their monthly or bimonthly ART. 68.9% (84/122) of them had been in care for at least two years and 68% (83/122) regarded their current sexual partnership as stable. Most stable partnerships were officially registered marriages, with fewer non-officially registered (religious or cultural) marriages or non-marital sexual partnerships.

Sexual partnership post-HIV diagnosis

The qualitative study revealed that women saw HIV diagnosis as a major event affecting their sexual life. Those diagnosed because of a positive partner reassessed their relationship with the partner. This sometimes led to strained relationships and divorce or separation. WLWH who decided to stay with the positive partner reasoned that they “already carried his virus so there’s no point for leaving”, and they “would not be able to find another partner because of [their] HIV status”. Other reasons why women stayed in their relationships included love and compassion for their husband and a desire to take care of them; the determination to stick together “in bad times and good times”; the belief that this would benefit the children; and their perception that they had already had too many marriages or partners.

“… I still care for [my husband], despite everything … I feel pity for him, too … And I have to make this work for the children … It’s also impossible for me to look for another partner now with this condition … When I lived separately from my husband for six months, it was difficult to find work on my own, while also taking care of the children.” (Marta, 32, WLWH who stayed with her positive husband)

WLWH who were diagnosed before their husbands had to consider status disclosure and, in cases where the husbands tested negative, the decision to stay married or not was primarily made by the husband.

Reasons for remarriage after a divorce or death of husband were: avoiding rumours about their divorced/widowed status (not differentiated in Indonesian language), falling in love, or wanting better financial security. Many women who remarried, however, ended up in economic hardship, as their husbands did not make much money and they had other children (from previous marriages) to support.

“… my husband is just a day labourer at a farm, but I’m content [being married to him]. It is better to have a husband. [In the sewing business] I have many male employees, and as a widow when I acted friendly with them they thought I was teasing them. Now they don’t think so anymore because I’m a married woman.” (Maemunah, 38, WLWH who remarried after her positive husband passed away)
Some female sex workers (FSWs) resumed sex work post-HIV diagnosis as they were still in debt to their pimp or due to the impossibility of finding new employment. Pimps and brothel management allowed HIV-positive FSWs to keep working, unlike massage parlours and karaoke bars, where positive FSWs were immediately expelled. Consequently, some FSWs from massage parlours and karaoke bars moved to work at brothels after testing positive. Brothels were also less strict

Table 1. Characteristics of the quantitative study participants ($N = 122$)

<table>
<thead>
<tr>
<th>Characteristics</th>
<th>Number</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age (in years), median (IQR)</td>
<td>35 (30–38.75)</td>
<td>NA</td>
</tr>
<tr>
<td>Education level</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Elementary</td>
<td>17</td>
<td>13.9</td>
</tr>
<tr>
<td>Secondary</td>
<td>71</td>
<td>58.2</td>
</tr>
<tr>
<td>Higher</td>
<td>34</td>
<td>27.9</td>
</tr>
<tr>
<td>Ethnicity</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Sundanese</td>
<td>94</td>
<td>77.0</td>
</tr>
<tr>
<td>Javanese</td>
<td>10</td>
<td>8.2</td>
</tr>
<tr>
<td>Others (Batak, Chinese, Malay, etc)</td>
<td>18</td>
<td>14.8</td>
</tr>
<tr>
<td>Birthplace</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Bandung city or surrounding towns</td>
<td>85</td>
<td>69.7</td>
</tr>
<tr>
<td>Another city in West Java</td>
<td>23</td>
<td>18.9</td>
</tr>
<tr>
<td>Another province in Indonesia</td>
<td>14</td>
<td>11.5</td>
</tr>
<tr>
<td>Duration of residence in the current city</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Since birth</td>
<td>46</td>
<td>37.7</td>
</tr>
<tr>
<td>&gt;5 years</td>
<td>43</td>
<td>35.2</td>
</tr>
<tr>
<td>1–5 years</td>
<td>25</td>
<td>20.5</td>
</tr>
<tr>
<td>&lt;1 years</td>
<td>8</td>
<td>6.6</td>
</tr>
<tr>
<td>Duration of ART at the HIV clinic</td>
<td></td>
<td></td>
</tr>
<tr>
<td>≤2 years</td>
<td>36</td>
<td>29.5</td>
</tr>
<tr>
<td>&gt;2 years (long term)</td>
<td>84</td>
<td>68.9</td>
</tr>
<tr>
<td>Have not initiated ART*</td>
<td>2</td>
<td>1.6</td>
</tr>
<tr>
<td>Current marital status</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Married, officially registered</td>
<td>67</td>
<td>54.9</td>
</tr>
<tr>
<td>Married, not officially registered</td>
<td>8</td>
<td>6.6</td>
</tr>
<tr>
<td>Widowed, not remarried</td>
<td>12</td>
<td>9.8</td>
</tr>
<tr>
<td>Divorced/separated, not remarried</td>
<td>25</td>
<td>20.5</td>
</tr>
<tr>
<td>Non-marital partnership</td>
<td>8</td>
<td>6.6</td>
</tr>
<tr>
<td>Single, never married</td>
<td>5</td>
<td>4.1</td>
</tr>
<tr>
<td>Duration of current partnership (in years), median (IQR)</td>
<td>5 (2–8)</td>
<td>NA</td>
</tr>
<tr>
<td>Number of times married</td>
<td></td>
<td></td>
</tr>
<tr>
<td>1</td>
<td>27</td>
<td>22.1</td>
</tr>
<tr>
<td>2</td>
<td>63</td>
<td>51.6</td>
</tr>
<tr>
<td>3</td>
<td>22</td>
<td>18.0</td>
</tr>
<tr>
<td>4</td>
<td>3</td>
<td>2.5</td>
</tr>
</tbody>
</table>

*These are newly diagnosed WLWH in the process of ART initiation.
than massage parlours and karaoke bars in enforcing condom use with clients in their premises.

After a divorce or death of their partner, some WLWH did not seek a new partnership for fear of transmitting HIV and of being rejected due to their status. The fear was enhanced by other women’s experiences of being rejected. Another reason for choosing to remain single is past relationship trauma due to infidelity or violence. Women in this situation concluded that taking care of their own health and their children was enough for their happiness.

In the quantitative survey, 37.7% (46/122) WLWH were diagnosed with HIV because of a positive partner. At the time of interview, 32.8% (40/122) WLWH had been together with their current partner since before the HIV diagnosis, 35.2% (43/122) were in a partnership that was started after diagnosis, and 32.0% (39/122) did not have a partner. In a few survey participants, partnership did not correspond to sexual activity. One WLWH who continued in the same partnership and six in new partnerships did not have sex with their partners in the past year.

Seven WLWH in the survey had had casual sex in the past year (0.06%). Five of these women (three are married) had casual sex with one partner who they regarded as a short-term boyfriend or regular “fuck buddy”. The other two were FSWs with multiple sex work clients. There is an overlap between WLWH who had had casual sex with a boyfriend and sex work clients. In the qualitative study, WLWH continued having casual sex with no condom immediately after HIV diagnosis while they were processing the acceptance of their status.

WLWH in the survey who had not had any sex in the past year mentioned reasons that corroborated our qualitative findings of WLWH who did not seek a new partnership. They only wanted sex in a marriage, were in a new relationship and needed more time before deciding to have sex, or did not trust that their partner would comply with prevention activity, i.e. condom use, due to their lack of knowledge and perception that downplayed the transmission risk.

Status disclosure to sexual partners

In the qualitative study, we found women who were diagnosed as the wife of positive men. Their diagnosis was started with status disclosure, assisted by a health provider, and typically done when the husband was already severely ill or dying with AIDS. Married women who were tested before their husbands were those who were tested at antenatal care, sex work venue, or due to symptoms. Disclosure to the woman’s husband or other family member in most cases was led by a health provider with the woman’s consent.

In subsequent partnerships, WLWH disclosed their status to a new partner without the assistance of a health provider; in fact, status disclosure was key to initiating partner testing, because it opened up the discussion about taking the partner to visit the HIV clinic to get more information and potentially get tested.

Women were careful in choosing when to disclose, but most of them did not consult anyone in making this decision. This resulted in delayed disclosure. Some of them believed that disclosing their status led their partner to cut communication with them.

“… I found out I was two months pregnant. I told him about [the pregnancy] and then we got a nikah siri.* … [the doctor at the HIV clinic] said I should disclose [my HIV status] to my husband and bring him to the clinic … When our son was four months old I finally told him. After that he never visited me again and did not return my calls … I only received money occasionally through one of his employees and they would not give me his new number.” (Wati, 35, WLWH who remarried after a divorce)

In other women, the fear of being rejected prevented them from disclosing their status, and it created a dilemma in relation to their childbearing wishes.

“We got married four months ago … I first met him as a client [at a massage parlour]. I have stopped working since we got married and moved back to [her hometown] while my husband works in Jakarta … he doesn’t know my status and I don’t know how to tell him … I wish we could have children, but I would have to tell him about this disease … So I don’t know what to do…” (Intan, 31, WLWH who got married for the first time after HIV diagnosis)

In the quantitative survey, 63.1% (77/122) were married at HIV diagnosis and 59.7% (46/77) were diagnosed after their partner was diagnosed.

*Marriage with only religious vows, officially unregistered, usually done if the bride or the groom is officially married to someone else.
Fewer women who were married at HIV diagnosis were tested earlier than their partner (28.6%, 22/77) or together with their partner (6.5%, 5/77). Of the women who were with a partner in the past year, 92.8% (77/83) disclosed their HIV status. The proportion of disclosure is similar between women who stayed with the same partner (N = 40) or those who had a new partner after HIV diagnosis (94.9% vs. 92.7%, p = 1). WLWH who had had casual sex in the past year (N = 7) did not disclose their HIV status to any of the casual sex partners.

### Condom use with sexual partners

We also qualitatively identified challenges in consistent condom use. Most WLWH said that their partners did not like using condoms, and FSWs could not enforce condom use on clients. To pressure her husband into using a condom, one woman deliberately avoiding other contraceptives, knowing that they both did not want more children. Condom use negotiation was also influenced by the type of relationship and HIV status disclosure. One woman’s sexual partner took her insistence on using a condom as a sign of lack of trust in the relationship.

> “… I wouldn’t call him a boyfriend, now that I have this disease I’m afraid to have boyfriends. And I insisted that we use condom every time. He didn’t like it, he thought I didn’t trust him.”

(Marni, 25, WLWH who had not disclosed her status to her new partner)

In the quantitative survey, we further compared duration of HIV care, risk profile (condom use, multiple partnership), HIV status disclosure, and partner testing between WLWH who stayed with the same partner (N = 40, 48.2%) and who had a new partner (N = 43, 51.8%) among WLWH who were with a partner in the past year (Table 2). Duration of care at the HIV clinic differed between the two groups (median and IQR of time since HIV diagnosis 3 (1–6) years vs. 6 (3–8) years, respectively, p = 0.002). Consistent condom use was low in both groups (always used condom in the past year 30.8% vs. 24.3%, respectively.

<table>
<thead>
<tr>
<th>Variable</th>
<th>Stayed with same partner (N = 40)</th>
<th>Had a new partner (N = 43)</th>
<th>P-value*</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age, median (IQR)</td>
<td>33.5 (29.75–39.25)</td>
<td>34.0 (30.5–38.0)</td>
<td>0.97</td>
</tr>
<tr>
<td>Time in care at HIV clinic (in years), median (IQR)</td>
<td>3 (1–6)</td>
<td>6 (3–8)</td>
<td>0.002</td>
</tr>
<tr>
<td>Have had sex with main partner in the past year</td>
<td>39 (97.5%)</td>
<td>37 (86.0%)</td>
<td></td>
</tr>
<tr>
<td>Condom use with main partner (asked if they have had sex in the past year)</td>
<td></td>
<td></td>
<td>0.46</td>
</tr>
<tr>
<td>Always</td>
<td>12 (30.8%)</td>
<td>9 (24.3%)</td>
<td></td>
</tr>
<tr>
<td>Often</td>
<td>10 (25.6%)</td>
<td>10 (27.0%)</td>
<td></td>
</tr>
<tr>
<td>Half of the time</td>
<td>3 (7.7%)</td>
<td>0 (0.0%)</td>
<td></td>
</tr>
<tr>
<td>Rarely</td>
<td>5 (12.8%)</td>
<td>8 (21.6%)</td>
<td></td>
</tr>
<tr>
<td>Never</td>
<td>9 (23.1%)</td>
<td>10 (27.0%)</td>
<td></td>
</tr>
<tr>
<td>Disclosure to partner</td>
<td>37 (94.9%)</td>
<td>38 (92.7%)</td>
<td>1</td>
</tr>
<tr>
<td>Partner HIV testing</td>
<td></td>
<td></td>
<td>&lt;0.001</td>
</tr>
<tr>
<td>Partner was tested</td>
<td>35 (89.7%)</td>
<td>22 (53.7%)</td>
<td></td>
</tr>
<tr>
<td>She does not know</td>
<td>3 (7.7%)</td>
<td>9 (22.0%)</td>
<td></td>
</tr>
<tr>
<td>Partner refused testing</td>
<td>1 (2.6%)</td>
<td>10 (24.4%)</td>
<td></td>
</tr>
</tbody>
</table>

*Wilcoxon rank-sum test for continuous variables, Fisher’s exact test for categorical variables with cells containing <5 observations.
Among WLWH who had had casual sex in the past year, a condom was used in their last sexual encounter but those who also had sex work in the past year claimed they rarely used it with clients.

**Partner testing and treatment**

Not all new partners of WLWH in the qualitative study got HIV tested, even after status disclosure. Women perceived partner’s reluctance to get tested as due to thinking they might have already contracted HIV or they did not care if they were to get infected.

“… [my husband] never got tested. He doesn’t want to. He knows about my status but he said he doesn’t care if he gets it too.” (Bintang, 25, WLWH who got married for the first time after HIV diagnosis)

Most WLWH tested at antenatal care had their husbands tested. Testing on the same day ensured status disclosure and partner testing, and in the cases where the husband was HIV-negative, he accepted and was supportive of her HIV diagnosis. One woman who did not have her husband tested on the same day nevertheless disclosed her status and made him accompany her to the HIV clinic for ART initiation. He declined HIV testing at the clinic, saying he was not ready and would be tested later. He later told her that he went to a public health centre and tested negative, but he never showed her the results; thus, she suspected him to have lied to her about getting tested.

In the quantitative survey, 69.9% (58/83) of participants knew the HIV status of their main sexual partners; 31.3% (26/83) had an HIV-positive partner. Among the positive partners, 18/26 received HIV care at the same clinic, 5/26 received care elsewhere, 1/26 was not in treatment, and two women were not sure about their partner’s treatment status. Thirty percent (25/83) of WLWH did not know their partner’s HIV status; 13.3% (11/83) said the partner had refused testing. More partners were tested among WLWH who stayed with the same partner than WLWH who formed new partnerships after HIV diagnosis (89.7% vs. 53.7% respectively, p < 0.001) (Table 2).

**Role of health providers**

The qualitative findings showed that policy for partner notification and testing differed from clinic to clinic and evolved over time. Health workers at the main referral HIV clinic, where almost 50% of all HIV patients in the city received ART, believed they had no legal power to enforce partner testing of patients in a non-marital partnership, so they only targeted partners of patients in officially registered marriages. Until 2016, they had a penalty for new patients who did not bring their spouses for testing; these patients only received ART for two weeks instead of one month.

Partner notification by a health provider mostly occurred when a woman was tested with her partner present, such as at antenatal care or when she was sick at the hospital. In a few cases, the health provider notified the partner without the woman’s consent.

“… the labour did not progress so they referred me to [a public hospital]… Then the doctor came and told me I was HIV-positive… He said I had to be referred to [a provincial referral hospital] for caesarean section and he asked who I wanted to disclose to … My aunt was there too and I preferred to tell her than to tell my husband… However, when we got to the [referral] hospital, another doctor asked my husband to sign [the consent form] before the surgery and told him my status…” (Mita, 24, WLWH who stayed with the same partner)

Women who started a new partnership post-HIV diagnosis had to disclose their status to the partner prior to taking him to an HIV clinic for further information and testing. In some cases, this led to inaccurate or incomplete information being shared with the partner about HIV transmission risk.

**Discussion**

This study found that despite some challenges, partner notification and testing are more likely to happen among patients with newly diagnosed HIV. Women with a longstanding HIV infection in Indonesia formed new partnerships and faced different challenges in status disclosure to and testing of the new partner. Not all WLWH in this study who were diagnosed as wives of HIV-positive men stayed with the husband. After a divorce or death of a husband, some of them formed new partnerships. There were barriers in initial status disclosure to new partners, prior to bringing them to a health provider for assistance with partner notification and testing. One of the main barriers to disclosure was the lack of stability in the sexual partnership. Furthermore, status disclosure
did not guarantee partner testing or consistent condom use. WLWH who continued to do sex work could only work at venues that did not enforce condom use and whose clients lacked condom use awareness. Some WLWH chose to remain single after a divorce or death of a husband due to fear of rejection, fear of transmitting HIV, or past relationship traumas. These women concluded that taking care of their children is enough for their happiness.

The findings presented in our study corroborated existing evidence on strategies to prevent HIV transmission to partners of PLWH. Other studies also found a higher proportion of partner testing among newly diagnosed HIV patients than among patients with longstanding infection; and that the two groups face different barriers to partner notification.\(^\text{36,37}\) Lack of interest in testing and the non-disclosure of HIV status were the main reasons for low uptake of HIV testing among partners of people with longstanding HIV in Thailand.\(^\text{38}\) Partners can be difficult to contact, particularly in casual or transactional sexual partnerships.\(^\text{39}\) Other than partner notification, women in less stable types of partnerships and FSWs need other transmission prevention strategies such as condom enforcement and ART to achieve viral suppression.\(^\text{40}\) The 2018 Indonesian national HIV policy of test and treat has included these strategies, but there are certain social barriers to its implementation, particularly for FSWs. WLWH in Indonesia with a history of sex work are a minority; however, they have many partners and intersecting social stigmas.\(^\text{41}\) Most FSWs were victims of trafficking and sexual exploitation, and few were doing consensual adult sex work, resulting in lack of agency of the FSWs due to power imbalances with their clients and their pimp or brothel manager.\(^\text{41}\) Due to shame and stigma about paying for sex, FSW clients are among the most difficult populations to reach even though the HIV prevalence in this population is higher than in the general population.\(^\text{42,43}\) Criminalisation of sex work and pressure from religious conservatives against condom enforcement further complicate HIV prevention in sex work settings.\(^\text{41,44}\)

In light of recent evidence that HIV transmission risk is negligible from PLWH who adhere to ART and maintained viral suppression at an undetectable level, status disclosure might not be a requisite for partner testing.\(^\text{45}\) In settings where stigma and violence could go unchecked, some PLWH preferred provider-assisted referrals for HIV testing for sexual or injecting partners without disclosure.\(^\text{46}\) However, status disclosure had benefits for the PLWH beyond the epidemiological benefits of transmission prevention. It increased social support, reduced depressive symptoms, and empowered WLWH with longstanding HIV.\(^\text{47–49}\) Women are more likely than men to disclose their HIV status for reasons related to emotional and financial support.\(^\text{45}\) Other studies found gender differences in preference for who to disclose to. Women seem to find disclosure easier when it is to family members rather than to the sexual partner and men find disclosure easier when it is to a heterosexual partner rather than to a homosexual partner.\(^\text{50,51}\) These findings suggest that disclosure preferences might be related to social acceptance and stigma of certain behaviour or practices. Given good communication with health workers, counselling about sexual partnerships could lead to decisions about status disclosure to sexual partners among WLWH.\(^\text{52}\) Indonesian social and cultural constructions of gender, however, have resulted in discrimination in healthcare settings against women with perceived undesirable behaviour (e.g. unmarried and sexually active).\(^\text{53,54}\) As such, perceptions of stigma, discrimination, and fear of abandonment have hindered disclosure.\(^\text{48,50,55}\)

The perceptions of shame and self-stigmatisation among WLWH in Indonesia preceded their HIV diagnosis, and health workers working with WLWH need to be aware of these and their intersectionality with the perception of societal expectations and norms about womanhood.\(^\text{31,56}\)

We found better partner testing coverage among women tested at antenatal care, where husbands were often tested on the same day. The success is likely due to couple testing, i.e. counselling and testing both the pregnant woman and her husband at the same time. Acceptance of couple testing is related to HIV risk awareness in both men and women and also to the availability of a supportive system.\(^\text{57,58}\) As antenatal care clinics are generally perceived as a female-only space, the partner has to be invited to couple testing. Formal invitation from the clinic is perceived to be more effective than a verbal request from a woman in making her partner come for couple testing in antenatal care.\(^\text{59,60}\) Gendered socioeconomic barriers to couple testing were found in Malawi; men are often away from home for economic
reasons and they fear exposure of their infidelity. A similar barrier could exist in Indonesia, particularly among women who are wives of MSM who marry women in order to adhere to heterosexual normality and fear exposure of their real sexual orientation.

This study has several limitations. With the focus on women, we did not interview any male partners. A study in another concentrated epidemic setting found higher HIV prevalence among sexual partners of female patients than of male patients; thus, it would be reasonable to prioritise the sexual partners of female patients in partner notification strategies. We also had a fairly low sample size in the quantitative strand of the study due to the constraints in the time-frame available to conduct the survey in the clinic, which limited the statistical power to detect significant differences between subgroups. The lack of intervention during this study is a strength because the results reflect the real-life situation. Mixed methods study design allowed capturing WLWH with different treatment profiles and partnership typology; both factors can be relevant to partner notification approaches. To our knowledge, this is the first study in Indonesia that uses mixed methods to investigate partner notification and testing among WLWH.

Women with a longstanding HIV infection formed new partnerships and faced challenges in status disclosure to and testing of the new partner. The national guidelines for partner notification and testing have included regular testing for people with longstanding HIV infection and this study recommends specific strategies in its implementation for WLWH. With specific interventions to reduce systematic discrimination from health providers, partnership counselling could aid disclosure among WLWH who formed new partnerships. WLWH in unstable partnerships require a different approach from those who are legally married. Partner notification might not be the most appropriate approach for clients of FSW, and other transmission prevention measures, such as condom enforcement and ensuring virological suppression among WLWH who are FSW, could be more important. Same day couple testing is effective at antenatal care and would improve coverage of overall HIV testing of pregnant women in Indonesia. These strategies, when applied in combination, would ensure that all WLWH with any duration of HIV infection are facilitated in disclosing their status to those who are in their support system and to prevent further transmission.

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Disclosure statement

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Data availability

For the qualitative study, the datasets generated and/or analyzed are not publicly available due to the fact that the participants did not consent to have their full interview summaries made publicly available. However, the Nvivo database with excerpts of the summaries relevant to the study is available from the corresponding author on reasonable request. For the quantitative study, the datasets used and/or analyzed are available from the corresponding author on reasonable request.

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Résumé
Cette étude à méthodologie mixte portait sur la révélation de la séropositivité au VIH et le dépi- stage du partenaire de femmes vivant avec le VIH dans un contexte épidémique concentré à Bandung, Indonésie. Le volet exploratoire qualita- tif a utilisé un échantillonnage théorique pour mener des entretiens semi-structurés avec 47 femmes infectées par le VIH se trouvant dans différentes situations de traitement antirétroviral. Le diagnostic du VIH a obligé les femmes à rééva- luer leurs partenariats sexuels. Certaines ont perdu leur partenaire suite à un décès ou un div- orce. Les femmes infectées de longue date par le VIH ont souvent noué de nouveaux partenariats. Elles ont révélé leur statut à leur nouveau parte- rieur sans aide des prestataires de soins de santé; le type et la stabilité du partenariat influen- çaient la décision de révéler leur séropositivité. La crainte du rejet a empêché la révélation initiale avant d’amener les nouveaux partenaires dans un centre de santé. La révélation n’a pas toujours

Resumen
Este estudio de métodos mixtos investigó la reve- lación del estado serológico con respecto al VIH y la realización de pruebas en parejas de mujeres que viven con VIH (MVV) en un entorno epidémico concentrado en Bandung, Indonesia. La fase cua- litativa exploratoria utilizó muestreo teórico para realizar entrevistas semiestructuradas con 47 mujeres infectadas por VIH en diversas etapas de terapia antirretroviral. La fase cuanti- tativa incluyó a 122 pacientes que recibieron trata- miento del VIH en un centro de referencia. Debido al diagnóstico de VIH, las mujeres reevaluaron su relación con su pareja sexual. Algunas perdieron a su pareja a causa de la muerte o del divorcio. Muchas de las mujeres que tenían infección por VIH de larga data formaron relaciones con nuevas parejas. Ellas revelaron su estado serológico a su nueva pareja sin la asistencia de prestadores de servicios de salud; el tipo y la estabilidad de la relación de pareja influyeron en la decisión de revelar su estado. El miedo al rechazo impidió la revelación inicial antes de llevar a la nueva pareja a un prestador de servicios de salud. La revelación
abouti au dépistage du partenaire en raison de la faible conscience des risques ou du déni du partenaire. En dépit d’une proportion similaire de révélation du statut au partenaire (92.8%), à peine 53.7% des nouveaux partenaires des femmes vivant avec le VIH ont été testés, contre 89,7% des partenaires testés chez les femmes vivant avec le VIH qui étaient restées avec le même partenaire. S’agissant des soins prénatals, où un dépistage avec résultat dans la journée était souvent réalisé pour les couples attendant un enfant, davantage de partenaires ont été testés. Dans l’ensemble, l’emploi suivi de préservatifs était faible et leur séropositivité a forcé les femmes continuant à pratiquer le commerce du sexe à travailler dans des environnements où l’emploi du préservatif n’était pas exigé. Les femmes séropositives se heurtent à des écueils pour révéler leur statut et pour faire dépister leur partenaire; des conseils de couple seraient utiles pour elles. Les directives sur la notification et le dépistage du partenaire devraient inclure des stratégies spécifiques pour les femmes qui ont une infection au VIH de longue date.

no siempre motivaba a la pareja a someterse a una prueba, debido a la poca conciencia del riesgo o a la negación de la pareja. A pesar de un porcentaje similar de revelación del estado serológico a la pareja (92.8%), solo el 53.7% de las nuevas parejas de MVV se sometieron a una prueba, en comparación con el 89.7% de las parejas que se sometieron a la prueba entre las MVV que continuaron con la misma pareja. En el servicio de atención prenatal, donde a menudo se realizaban pruebas de VIH el mismo día para parejas embarazadas, un mayor número de parejas se sometió a la prueba. En general, el uso sistemático del condón era bajo y el estado de VIH forzaba a las MVV que continuaban realizando trabajo sexual a trabajar en entornos donde no se exigía el uso de condones. Las MVV enfrentan barreras a la revelación de su estado de VIH y a la realización de la prueba en su pareja, por lo cual se beneficiarían de recibir consejería sobre su relación de pareja. Las directrices sobre la notificación a parejas y la realización de pruebas en parejas deben incluir estrategias específicas para las mujeres con infección por VIH de larga data.