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Article *in* Sexual and Reproductive Health Matters · December 2020

DOI: 10.1080/26410397.2020.1848003

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ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/zrhm21

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To cite this article: Najmah , Sari Andajani & Sharyn Graham Davies (2020) Perceptions of and barriers to HIV testing of women in Indonesia, Sexual and Reproductive Health Matters, 28:2, 1848003, DOI: 10.1080/26410397.2020.1848003

To link to this article: https://doi.org/10.1080/26410397.2020.1848003

RESEARCH ARTICLE

SRHM SEXUAL AND REPRODUCTIVE HEALTH MATTERS
MORE THAN A JOURNAL

Perceptions of and barriers to HIV testing of women in Indonesia

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Abstract: *Indonesia's 2014 health reforms advocated for universal health coverage for all Indonesians. The reforms made provision for integrated human immunodeficiency virus (HIV) programmes, with testing available at community health centres and hospitals for pregnant women and women of childbearing age. The question remains, though, as to whether testing has been effective. This article focuses on barriers women face accessing HIV testing and presents findings from the experiences of 18 HIV-positive women. To triangulate findings, interviews were conducted with 26 health workers, 9 non-governmental organisation workers and 12 HIV stakeholders. The article examines barriers to pregnant women's access to HIV tests, showing that barriers relate to women not having reproductive health rights. It highlights reproductive rights noted in the Respectful Maternity Care Charter, and violations to them relevant to HIV testing in pregnancy. Five reported rights violations include: women being unable to access information; being unable to make informed decisions; having no right to confidentiality and privacy; experiencing ongoing discrimination; and having no right to timely HIV testing. The failure of Indonesia to protect these rights contributes to women being denied HIV testing. Findings show the need for increased HIV testing services for pregnant women and assert that health personnel and programme policy-makers need to be held accountable for the protection and fulfilment of women's rights in respect of HIV testing. The findings show that policy makers must make changes to ensure health services improve, health professionals must be better trained, and women's socio-cultural and political contexts must be considered.* DOI: 10.1080/26410397.2020.1848003

Keywords: HIV tests, married women, human rights violations, reproductive rights, universal health coverage, Indonesia

Introduction

The 2014 health reforms in Indonesia advocated for increased universal health coverage (UHC) for all Indonesians, including the provision of integrated human immunodeficiency virus (HIV) programmes, with HIV testing to be available at community health centres and hospitals for pregnant women and women of childbearing age.[1–3] Annually in Indonesia, 40% of new HIV cases occur in women of childbearing age.[4] These women fall outside prescribed high-risk groups [i.e. commercial sex workers (CSWs), injecting drug users (IDUs) and men who have sex with men (MSM)] (Table 1). The steep increase in HIV prevalence among women in the general population in the past decade is a proxy indicator for HIV transmission to children, and HIV policies and programmes cannot remain ignorant of HIV transmission in women, especially among pregnant women.[6]

Pregnancy occurs among women living with HIV[6,7] and, as such, infants are vulnerable to HIV transmission from their mothers, through pregnancy, delivery, and/or breastfeeding.[8,9] An HIV prevalence of 0.4% in pregnant women would indicate that approximately 25,000 women, out of six million pregnant women, are HIV positive at any one time in Indonesia.[10] Of concern is that pregnant women often find out their HIV status in the late stage of pregnancy, resulting in late

Table 1. HIV prevalence in different groups in Indonesia (population of 270 million)

	Prevalence risk (%)	Estimated number PLWHIV[a]/high-risk groups[b]
General population		
All adults aged 15 and over	0.4	620,000[a]
Women	0.3	220,000[a]
Pregnant women	0.4	25,000[a]
Men	0.5	420,000[a]
High-risk group		
Intravenous drug users	28.8	33,500[b]
Men who have sex with men	25.8	754,300[b]
Female sex workers	7.2	226,800[b]
Transgender people	24.8	38,900[b]
Men who access prostitutes	–	5,244,064[b]

[a] People living with HIV.
[b] Estimated number of high risk groups to contracted HIV (not all HIV-positive); prevalence risk of HIV in the general population in Papua > 4%.
Source: (MoH, 2018[4]; UNAIDS, 2020[5]).

treatment for preventing mother to child transmission (PMTCT).[9,11] Without timely and effective HIV treatment during pregnancy, half of HIV-positive pregnant women will give birth to HIV-positive babies.[12,13] Further, without antiretroviral therapy (ARV), those infants will likely die before their second birthday.[9,14] Less than 10% of pregnant women in Indonesia access PMTCT services,[8] and missed opportunities for early HIV screening and treatment for pregnant women remain a huge challenge.

The promotion and protection of women's rights to health care, including early HIV screening and timely and relevant HIV treatment, is central to the UHC goal.[15,16] At the global level, women's right to health care is well recorded in a number of international conventions including the 1985 International Convention on the Elimination of All Forms of Discrimination Against Women, and the Cairo International Conference on Population and Development Programme of Action ICPD (PoA) in 1994.[17] At the national level, the Indonesian government passed a number of regulations between 2013 and 2017, including the 2014 Universal Health Care Policy to include integrated HIV testing in antenatal clinics and ARV treatment for women and children in PMTCT programmes.[18–20] Other regulations include a mandatory offer of HIV testing in antenatal care (ANC) services; provider-initiated HIV testing and counselling; comprehensive PMTCT and guidance to services; and the fiscal responsibilities for all parties and ministries involved.[1,21,22] With continuing high HIV prevalence in a number of provinces, like Papua (a generalised epidemic)* and Jakarta, Bali, East Java, West Java and Riau (concentrated epidemics)* amongst MSM, CSWs and IDUs, Indonesia needs to significantly scale up its HIV screening and ARV treatment in PMTCT.[9,24,25]

Nevertheless, widespread inequalities in accessing health services remain.[18] For example, in Palembang, our study field, compulsory HIV screening in ANC was only introduced in 2017; at the time of this study in early 2017, there were only 16 voluntary counselling and testing (VCT) centres, mostly located in hospital-based settings, with only three in *puskesmas* (local community health clinics) settings. At the end of 2017, all

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*A generalised epidemic is where most new infections are from heterosexual contact in the general population. A concentrated HIV epidemic means HIV has spread rapidly in one or more defined sub-populations but is not well-established in the general population.[22]

41 *puskesmas* in Palembang provided HIV testing as a part of PMTCT services, and 12 new VCT centres were established.[26]

While Indonesia has implemented policies on HIV testing, uptake remains poor, with various challenges, such as poor referral mechanisms.[2,27] For instance, when a pregnant woman gets referred, she may find it difficult to travel to the VCT clinic (e.g. the clinic is too far or the clinic's opening hours do not work for women).[2,27,28] At the same time, women living with HIV are highly stigmatised in Indonesian societies, making healthcare providers feel hesitant or reluctant to refer women to have HIV tests; they do not want to shame or insult their clients.[27,29] In the remainder of this article, we examine barriers and challenges that pregnant women face in accessing HIV testing during pregnancy, using a framework of women's sexual and reproductive rights. The Respectful Maternity Care Charter (RMCC) was introduced in Indonesia and worldwide by the White Ribbon Alliance, adopting 10 universal human rights indicators for women's and new-borns' rights in maternity health care. The RMCC was chosen as the best platform for our examination because it allows analysis of the rights violations women faced in accessing HIV tests in Indonesia.[30,31] Some of the 10 universal rights include: (1) right to information; (2) right to independent informed decision-making; (3) right to privacy and confidentiality; (4) right to respectful services (non-discrimination and dignity and care); and (5) right to timely treatment and attainable health care.

In this article, we focus on common sexual and reproductive rights violations reflected in the experiences of 18 HIV-positive women participants when accessing HIV testing in Palembang, South Sumatra. These women had either been married or were married to heterosexual men at the time of the study. A clear understanding of these barriers will provide a platform for the development of policies and programmes that will support women. For example, our findings can inform policies and programmes that aim to: raise awareness of women's rights; guarantee health care delivery; increase capacity for health advocates to participate in human rights processes; and support health care professionals in providing respectful care and holding the government to account to fulfil these rights.[30] Previous studies on barriers to HIV testing in women, such as Badriah et al.[28] in Jakarta; Butt,[32] Lumbantoruan et al.,[33] and Munro and McIntyre[34] in Papua, would have revealed examples of human rights violations. Yet those studies did not use the framework of sexual and reproductive rights as their analytical focus.

Methodology

This study acknowledges HIV-positive women as experts in respect of their own HIV journeys. Women in this research were central to the production of knowledge and understanding of existing policies and practices regarding HIV testing. Following Lykes and Crosby,[35] women in this study were given a safe and collective space, and trustworthy partnerships with the researchers, to have an open dialogue and critical discussion on matters relevant to HIV testing.[35] The voices of HIV-positive women were honoured, as well as those of other participants, like health workers, non-governmental organisation (NGO) workers, and policy makers, to triangulate knowledge of how women were accessing HIV testing during pregnancy. The triangulation process is a form of getting feedback on preliminary results or testing results with other research participants.[26]

Selection of participants

Participants in this study included 18 HIV-positive women, aged 21–47 years, and 26 healthcare providers (12 midwives, 11 medical doctors, 2 obstetricians, and 1 paediatrician), 12 policymakers, and 9 NGO peer-support workers. Participants were recruited through purposive sampling. The inclusion criteria of the HIV-positive women were: (1) of reproductive age; (2) living in Palembang, South Sumatra; and (3) available to join a series of focus group discussions (FGDs) or interviews. An advertisement was sent to NGOs and health service workers and included at local VCT clinics. For other groups, a formal letter of invitation was sent to each targeted institution related to HIV programmes for women. This article, however, focuses mainly on the narratives produced by the 18 HIV+ women and a few health workers, to best illustrate examples of the violations of women's reproductive health rights in respect to accessing HIV testing.

Ethical issues, including asking for consent from participants to use interview/FGD transcripts, respecting participants' rights to privacy and confidentiality for publications, and minimising risks for both the participants and the researcher, were discussed with the first author, including their rights to withdraw from our study. Protection of participants from any deceit, harm, and coercion was taken seriously in this research; it was essential to be able to keep to the cultural values, social, and ethnic diversities of the participants. Informed consent was obtained from each participant. Ethics approval was obtained from the Auckland University of Technology Ethics Committee on 7 March 2017 (Reference No. 17/22) and from the Research Ethics Committee of the Faculty of Medicine of Sriwijaya University (Reference No. 39/keprsmhfkunsri/2017) on 15 March 2017.

Women's life context

Table 2 presents the demographic and reproductive status of the 18 HIV-positive women who participated in this study. Twelve were married and six were widows. Of those 12 who were married, eight were in their second marriage. Of the eight in their second marriage, six had former husbands who had died from HIV and two had divorced from their first husband before they were diagnosed with HIV.

All 18 women were aware of their vulnerability to HIV. Twelve women believed that they were infected by their husbands who were either former IDUs ($n = 6$), and/or frequent customers of commercial sex workers ($n = 5$), and/or living in a polygamous marriage ($n = 3$), and/or having sex with men ($n = 1$). All but two of the women were not aware of having high risk in their own sexual behaviour. Two women had histories of intravenous drug use and having multiple sexual partners without practising safe sex.

The women had between one and six children and had lived with HIV for at least two years (based on the CD4 level – the level of white blood cells – at first HIV test).[36] Most of the women became aware of their own HIV status following their husbands' or children's sickness or death. Three women had HIV-positive children. Two had experienced stillbirths but they were not aware of what had caused it. Four women had children, all under 18 months old, taking ARV prophylactic treatment to reduce MTCT.

All except one participant identified themselves as housewives (*ibu rumah tangga*). At the time of this study, one woman, Mona, was working full time. The term *ibu rumah tangga* is a generic term used in the Indonesian context to refer to married women who are either fully financially dependent on their husbands or in informal employment sectors. For example, participants who worked as an hourly paid housemaid (cleaning other people's houses) or running a small *warung* (a bric-a-brac stall) referred to themselves as *ibu rumah tangga*. Although 17 participants declared themselves as *ibu rumah tangga*, seven were fully financially dependent on their husbands and 10 had worked in the informal sector, having an online business and opening a small stall. Six participants who were widows also regarded themselves as *ibu rumah tangga,* even when they were the primary income-earner or the breadwinner of their families. Seven participants owned their houses; six lived in shared accommodation with their extended families (in-laws and siblings). Five rented a small room or a small house. The participants had completed at least 12 years of schooling.

Field research

The field research, in Palembang, South Sumatra, was conducted over four months from March to July 2017 and included a series of group discussions, interviews, and participant observations by the first author (N). Palembang was selected because the first author was born and raised in Palembang and has worked for a number of years with various organisations working with IDUs and HIV in this city. She has good community connections that facilitated the research. She is also fluent in the local language. Being aware of the sensitive nature of research with women living with HIV and having a former connection with relevant persons and institutions working with HIV programmes would enhance the success of the field research. All interviews and communications with participants were conducted in Bahasa Indonesia and local Palembang dialect.

Prior to the field research, two pilot trials were conducted to examine the relevance of the research plan, recruitment of participants, research instruments, and any local norms and customs that the researchers should respect. These trials were conducted in Auckland (New Zealand) and in Palembang (Indonesia). The Auckland trial included group discussions with two groups of Indonesian women living and/or studying in Auckland. The trial in Palembang included two HIV-positive women, in a few meetings. The research plan and interview schedules were finalised following these two trials.

Table 2. Demographic profile and HIV-related status of the 18 HIV+ participants

No	Pseudonym	First CD4* (cells/mm^3)	Year of HIV diagnosis	Age	Marital status	PMTCT access**	HIV status of husband	No. of children alive	Education level	Notes
1	Mira	350	2015	21	Married	Yes	Positive	2	Senior High School	1st marriage, monogamous; 1st child HIV free; 2nd child took prophylaxis, vaginal delivery, confirmed HIV free December 2017; Bisexual husband
2	Bulan	40	2013	46	Widow	No	Positive	1	Senior High School	Divorced from 1st husband; 2nd husband deceased, was HIV+; 2nd marriage, polygamous
3	Nika	292	2016	22	Married	Yes	Negative	3	Elementary School	1st marriage, monogamous; 1st and 2nd child HIV free; 3rd child taking prophylaxis
4	Alung	100	2012	37	Married	No	Negative	3	Elementary School	2nd marriage as a 2nd wife; one HIV+ child and one deceased child
5	Rini	400	2011	41	Widow	No	Positive	3	Senior High School	Deceased husband was HIV+
6	Mawar	300	2011	41	Married	No	Negative	2	Senior High School	2nd marriage; polygamous; 1st deceased husband was HIV+; 2nd husband HIV neg, former IDU
7	Mela	300	2014	42	Widow	No	Positive	3	Senior High School	Deceased husband was HIV+; Husband was an IDU
8	Nina	329	2012	32	Married	No	Negative	3	Senior High School	2nd marriage; monogamous; 1st husband deceased, was HIV+; 1st husband was an IDU; 2nd husband HIV neg
9	Mano	300	2016	25	Widow	No	Positive	1	Senior High School	Deceased husband was HIV+; One child was HIV neg.; Former prostitute

10	Oneng	155	2016	41	Widow	No	Positive	6	Senior High School	Deceased husband was HIV+; Children 1–5 were HIV neg.; Sixth child was HIV+
11	Sinta	–	2012	41	Widow	No	Unknown	1	Senior High School	Deceased husband never took an HIV test Former IDU
12	Mona	500	2012	30	Married	Yes	Negative	2	University	2nd marriage, monogamous; 1st husband deceased, HIV+ and IDU 2nd husband HIV neg.; 1st child was HIV free; 2nd child taking prophylaxis
13	Putri	292	2007	35	Married	Yes	Positive	2	Senior High School	1st marriage; monogamous; 1st and 2nd child HIV free; 2nd child taking prophylaxis Husband was former IDU
14	Maya	400	2015	33	Married	No	Negative	3	Elementary School	1st husband divorced, was HIV neg.; 2nd husband HIV neg.; Former prostitute
15	Oda	290	2017	30	Married	No	Negative	3	Senior High School	1st marriage, monogamous; 1st and 2nd children HIV free; 3rd child HIV+
16	Xani	300	2007	35	Married	Yes	Positive	3	University	1st marriage, monogamous. Husband was former IDU
17	Bunga	350	2017	30	Married	Yes	Negative	1	Senior High School	2nd marriage, monogamous; 1st husband deceased, unknown HIV status; 1st child taking prophylaxis
18	Mulan	400	2012	28	Married	Yes	Negative	1	Senior High School	2nd marriage, polygamous; 1st husband deceased, HIV+; 1st child died of pneumonia, a sign of HIV; 2nd child taking prophylaxis; 2nd husband was former IDU

Notes: *CD4 (cells/mm^3): CD4 cell count, the level of white blood cells, is frequently used to measure how long someone has been infected with HIV. PLWHIV who had a CD4 of less than 200 cell/mm^3, 200–350 cells/mm^3 and over 350 cells/mm^3 were estimated to have contracted HIV about eight, four and one year prior, respectively.[38] **PMTCT access relates to comprehensive PMTCT services, including antenatal HIV testing, antiretroviral treatment during pregnancy and after delivery, prophylaxis treatment for babies born to HIV-positive mothers, and formula feeding.

Of the 18 HIV-positive women in this study, 11 formed two focus groups: Group A (5 members) and Group B (6 members). Women chose their own groups with no input from the researchers. Six focus group sessions of two hours each were conducted with each group. Twelve group discussions were carried out over a two-month period. The remaining seven women opted for individual interviews. Each woman was visited one to three times, depending on their availability. Each visit lasted for about an hour. Some also asked for follow-up online communication using Facebook and WhatsApp. Places for interviews and group discussion were at the discretion of participants and included participants' houses, offices, community health centres, hospitals, restaurants, and parks. All interactions with women were conducted in a safe, physical environment chosen by the women. This allowed all participants to have more control of their space and be in a place where they felt safe and comfortable, while at the same time, maintaining confidentiality and privacy [see, for example, Ponic et al.[37] and Najmah[26]].

Data analysis

Narratives from interviews and group discussions were transcribed verbatim. Field notes were recorded in both Bahasa Indonesia and English. The interpretations of the women's reflections and presentations were coded in their original language by the first author. The second author (SA) was also born in Indonesia and speaks fluent Bahasa Indonesia. SA had nearly 30 years of working in the area of gender health and sexual and reproductive rights, particularly in Indonesia, and in other parts of the Asia and Pacific region. The first two authors worked closely together on the Indonesian transcription throughout the coding stages, making meaning of the contexts presented by the women, and developing themes from the coding, before translating relevant quotes into English. The third author (SGD) was born in Australia and has worked for over 15 years in research projects in Indonesia relating to gender and identity.

To ensure consistency, regular fortnightly meetings were conducted between the authors to discuss emerging themes, categorisation, and links between codes and meanings, to enhance data interpretation. Transcriptions produced during the focus groups and interviews were cross-checked with field notes and visual images. Five main themes of rights violations emerged: right to information, right to informed decision-making, right to confidentiality and privacy, right to dignity and care, and right to timely services (Table 3). Thematic analysis was performed by applying the steps of coding set out by Saldana[38] across different themes of women's sexual and reproductive rights iterated in the Respectful Maternity Care Charter.

Findings and discussion

Table 3 depicts domains of disrespect and abuse and associated human rights violations against participants living with HIV. Out of 18 women, 12 felt they were lacking information with regard to HIV results of their husband, their children, or their own. Of these 12 women, five had never been aware of any available HIV testing nor had they ever received any information that raised their awareness of the importance of HIV testing. These five women only found out about their HIV in late pregnancy, after the death or illness of their husbands, children, or when they themselves had fallen ill. One in three experienced breaches of their privacy and confidentiality, when their HIV testing results were shared with other health workers, family members, or neighbours without their permission. In the next section, we present stories of Bunga, Oneng, Nika, shared during interviews and/or FGDs.

According to Indonesian MoH Regulations, it is not ethical to disclose patients' information without their approval.[39] Patients may request an HIV test voluntarily. A health worker or counsellor can also initiate and send a patient for an HIV test, known as a "provider's initiated test". In either case, patients have the right to counselling and informed consent. Failure by the health provider to explain the following rights to the patients, is considered a breach of patient's rights to informed consent [Permenkes number 74 in 2014, Guidelines of HIV test and counselling].[39]

Stories of Bunga and Oneng: not getting the right information

Oneng (41 years old, low-income family, a widow living in an urban area) and Bunga (30 years old, middle-income family, second marriage, living in an urban area) shared stories during focus group discussions and interview, respectively. Both Oneng and Bunga were financially dependent on their husband. From their stories, we learned about the breach of women's right to information,

Table 3. Associated human rights violations in HIV testing HIV of 18 HIV-positive women

Pseudonym	Violations of human rights in reproductive health and HIV services				
	Rights to information[a]	Rights to informed decision-making[a]	Rights to confidentiality[b]	Rights to dignity and non-discrimination[c]	Rights to timely and best services[d]
Mira			V	v	v
Bulan	v				v
Nika	v	v	v	v	
Alung	v				v
Rini	v				v
Mawar	v			v	v
Mela	v				v
Nina					v
Mano	v		v	v	
Oneng	v			v	v
Sinta	v		v	v	
Mona			v	v	
Putri			v	v	v
Maya	v				v
Oda				v	v
Xani				v	v
Bunga	v	v		v	
Mulan	v				v

Notes:

[a] Rights to information may include rights to informed consent, reasons for referral, reasons for denied services, information on choices of services available, and the rights to bring support person/s to services.

[b] Right to confidentiality and privacy.

[c] Right to equality, freedom from discrimination, equitable care & right to dignity and respect.

[d] Right to timely healthcare and to the highest attainable level of health.

Adapted from Butt[32] and Lumbantoruan et al.[33]

confidentiality, and privacy and how these rights are intertwined.

Bunga recalled her caesarean operation was cancelled in a private hospital, and she was referred to a public hospital. Upon her arrival at the public hospital, one of the doctors asked her husband "*did you know why your wife was referred to us?*". Bunga's husband said that the doctor at the private hospital was only saying that their baby was in a breech position. The doctor replied "*No, your wife is HIV positive* *and Hepatitis B positive"* (Bunga). In shock, Bunga cried for three days while she was waiting for scheduled caesarean surgery in this public hospital.

Oneng's story was about her shock after being told by her doctor that her youngest daughter was HIV positive: "*Angrily, I asked the doctor 'How come my daughter got this HIV?' The doctor replied But (Mam), you should know better than me how HIV was transmitted to your daughter"* (Oneng).

Both Bunga and Oneng were shocked when they received the news of their positive HIV test. Both were made aware of their HIV status in late stages, only after Bunga's HIV test before she delivered her baby and after Oneng's child had become sick. In both cases, the doctors were not straightforward with their information; instead, they referred Bunga to another hospital without giving the right information for referral, while Oneng was offered an HIV test after her youngest daughter got ill and was diagnosed with HIV. This occurred one year after Oneng's husband passed away due to diseases related to AIDS. In other women's stories, the husband's family, such as mother-in-law and brother-in-law, may have been informed of the HIV status of the women's husbands in health settings, but they chose not to disclose the husband's HIV status to the women. Najmah et al. describe a similar story of a 46-year-old woman, from a middle-income family, living in an urban area, in a second, polygamous marriage.[40]

Nika's story: breach of privacy and confidentiality

Nika (22-years-old, low-income family, first marriage, living in a rural area), retold to her peers during an FGD how a midwife had disclosed her HIV status to Nika's neighbours. In 2016, Nika was referred by her midwife to have a blood test in a *puskesmas*, including an HIV test, without Nika's consent. Nika did not know she was tested for HIV and to her horror the test result was positive and the news about her HIV status spread widely in her neighbourhood.

"*At first, I thought, I was just having a normal blood test. After I took the test, a health worker told me: 'please wait outside'. I was waiting for hours until the last patient had gone home. 'What happened with me?' I asked myself wearily. I asked another health worker. She said 'No worries, just sit down, and a nurse will come to get you soon.' Finally, a counsellor came and told me that my HIV test was positive. To my shock … and three days later, a midwife, who was my neighbour and work in that puskesmas, was gossiping with my neighbours about my HIV status. My family and I were expelled from our village straight away."*

Angry neighbours then forced Nika and her husband (Maman) and two children to move out of the village. The family moved to Palembang city and rented a small one-bedroom or *kos-kosan* (4×5 m^2), with shared washing rooms. Nika said that she and her family were victims of social gossiping and social stigma:

"*Social stigma … had cornered me … failed me, punished me … as if I were not a good woman … not a good mother … watch your mouth. those people working in health … get the right education*." (Nika)

Maman often expressed his regrets, telling Nika, "*had I known that you were asked to have an HIV test in that puskesmas, I would have forbidden you to take it"* (Nika). Maman (HIV-negative) continued to support Nika and Nika adhered to ARV treatment. Their baby was given prophylactic treatment after birth. Nika decided to have a tubectomy following the birth of her third child, suggested by her doctor. Nika consented.

Nika's story revealed negative and traumatic experiences that she and her family went through following an HIV test, when Nika's privacy was breached by her midwife. Nika's experience was later shared with groups of healthcare workers such as NGO workers, midwives, medical doctors, and HIV policy makers, to illustrate the violation of Nika's right to confidentiality and privacy in HIV testing. Upon discussing Nika's story, opinions of health workers and policy makers were somewhat divided. One group believed that the breach of privacy was "normal" as health workers, in the spirit of solidarity, want to protect their peers to be cautious of HIV-positive patients. This opinion could reflect a manifestation of institutionalised stigma against people living HIV, within Indonesian health services. The other group was supportive of patients' right to confidentiality and privacy. Ministry of Health Regulations, No. 74/2014 on Guidelines for HIV Testing and Counselling (VCT), notes that it is unethical to disclose patients' information without patients' approval, including to their spouse.[39]

Violations of patients' confidentiality in HIV testing have also been reported in Sub-Saharan Africa and some Asian countries, such as Vietnam and India.[41–43] In these studies, moral judgement and socio-cultural stigma are argued to be at the root of the violation of patients' right to confidentiality and privacy as well as the right to get correct information[32,44] (see Mira's story in Najmah et al).[45]

Stories of Anti and Lela: needing a husband's permission for HIV testing

Stories of Anti and Lela were retold by a specialist obstetric gynaecologist, who participated in an interview. Anti and Lela were patients of Doctor Didi (a pseudonym), a senior male obstetrician in a private hospital in Palembang. Anti visited his clinic after experiencing a yellow and white milky discharge from her vagina. She was initially treated by another physician for her sexually transmitted infection (STI) and referred to Didi for a follow-up HIV test. Anti came to him with her husband. He recalled seeing Anti looking very weak. Following an individual consultation for HIV, Didi suggested that Anti have an HIV test. Anti's husband was very upset and insisted that "it was impossible for his wife to have HIV". Didi explained to him that it was important to have the HIV test done so Anti could get the right treatment. Anti's husband finally agreed and Anti's test was negative. On a separate occasion, disgusted at Didi, Anti's husband said: "*I told you so! It is not possible for my wife to get infected with HIV*". In another story, Lela came to Doctor Didi's practice to ask for an HIV test. She was suspicious that her husband was having an extramarital affair and was concerned about her reproductive health as she had had three previous miscarriages. Lela's husband refused to give permission for Lela to have the test. Lela's request for HIV testing was then denied. Lela's husband, a high-profile local member of parliament, told Lela and Didi: "*Never in my life I would let you have that [HIV] test. I am not naughty*".

According to the Indonesian Ministry of Health Regulation No. 74, HIV tests and counselling, including voluntary or provider-initiated testing, should respect and protect patients' rights to informed consent and confidentiality across all services: HIV testing, counselling, and HIV prevention and treatment.[39] There is no requirement for a healthcare worker to seek permission for any of those services from patients' partners.

Of interest here, women would often feel ashamed when presenting themselves to a doctor's clinic with symptoms of STIs. Due to shame, the woman may choose to suffer in silence until the condition gets worse or becomes unbearable. Here, the comment made by Lela's husband that "I am not naughty" indirectly suggested that Lela could be the one having sexual affairs and to be blamed. Studies by Bennett (Bennett 2015) and Najmah (Najmah 2019) also found doctors' reluctance to offer testing for STIs or HIV to women's husbands, due to fears of causing marriage breakups and exposing the couples to shaming.[28](47)

Denial of Lela's request for HIV testing, however, was unacceptable. It was associated with fears from a health professional of causing marriage break-ups, disharmonies, insults, and shame to their patients and of losing their patients in consequence, as reported elsewhere.[27] Here, Didi was faced with dilemmas. He recognised the right of his patients to HIV testing and understood that by law the women did not need permission from the husbands. However, he was also aware that he could jeopardise his reputation and that of his institution, if women were given an HIV test without their husbands' permission. Didi recalled an experience of one of his colleagues who was blackmailed after performing an HIV test without the patient's husband's permission.

Women's subordination in marriage is a key reason why women are denied a right to health care. Anti and Lela were aware of their health needs, yet were powerless to take control of them, or exercise their rights. Without obtaining their husband's permission, married women like Anti are impeded by patriarchal values that position married women as subordinate to their husbands.

Further research can extend our conclusions by incorporating the voices of more women and the limits of the rights they have to access healthcare. We anticipate women throughout Indonesia will have similar stories to tell.

Recommendations

A primary finding of this study is that violations of women's reproductive rights in respect of HIV testing contribute to barriers to access HIV services in Indonesia. Violations of women's rights to information, informed decision-making, privacy and confidentiality, and timely service were evident in this study. Existing socio-cultural and ideological values, such as HIV stigma against people living with HIV, the normalisation of institutional stigma, and patriarchal values intersected to contribute to difficulties for women in the general population to access HIV testing.

Overcoming rights violations requires acknowledgment that rights violations exist, and making government accountable to address those human rights violations. Multiple and inter-sectoral approaches are needed at individual and interpersonal levels, and in institutional and public policies. First, at the individual and interpersonal level, women and their partners need to be aware of women's rights to information, informed decision, privacy and confidentiality, non-discrimination, and timely and optimal health care. Second, training of healthcare professionals needs to highlight the connection between HIV testing services and human rights guarantees. Third, human rights activists, programme leaders, and policy makers need to build capacities for advocates for a rights-based approach in HIV testing. Fourth, monitoring and evaluation of HIV testing in Indonesia must accommodate relevant human rights indicators that serve as a foundation for holding government accountable for the fulfilment of women's rights to health in HIV testing. Lastly, a supportive healthy working environment is central to ethical professionalism in HIV testing services and to reducing institutionalised stigmatisation. For example, an open discussion within health care delivery, and recognition of the need to use simple, relevant, non-loaded language in HIV testing services, could be a good step in reducing HIV stigma across health services.

Funding

This work was supported by Auckland University of Technology, New Zealand [PhD funding]; New Zealand Scholarship, Ministry of Foreign Affairs and Trade (MFAT) [PhD scholarship]; Sriwijaya University [PhD research funding].

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Résumé

Les réformes de santé engagées par l'Indonésie en 2014 plaident pour une couverture santé universelle (CSU) pour tous les Indonésiens. Les réformes ont prévu des programmes intégrés de lutte contre le virus de l'immunodéficience humaine (VIH), avec un dépistage disponible dans les centres de santé communautaires et les hôpitaux pour les femmes enceintes et en âge de procréer. On ignore cependant si le dépistage a été efficace. Cet article est axé sur les obstacles que les femmes rencontrent pour avoir accès au dépistage du VIH et présente les conclusions tirées de l'expérience de 18 femmes séropositives au VIH. Pour trianguler les résultats, des entretiens ont été réalisés avec 26 agents de santé, 9 employés d'organisations non gouvernementales et 12 personnes concernées par le VIH. Cet article examine les obstacles à l'accès des femmes enceintes aux tests du VIH et montre que ces obstacles se rapportent au manque de droits de santé reproductive des femmes. Il met en lumière les droits reproductifs mentionnés dans la charte des soins de maternité respectueux et les violations de ces droits en rapport avec le dépistage du VIH pendant la grossesse. Cinq violations des droits ont été rapportées: l'impossibilité pour les femmes d'avoir accès aux informations; l'impossibilité de prendre des décisions éclairées; le déni du droit à la confidentialité et la vie privée; des manifestations suivies de discrimination; le déni du droit à un dépistage rapide du VIH. L'incapacité de l'Indonésie à protéger ces droits contribue au refus du dépistage que les femmes se voient opposer. Les conclusions montrent qu'il est nécessaire d'augmenter les services de dépistage du VIH pour les femmes enceintes et de veiller à ce que le personnel de santé et les décideurs des programmes rendent compte de la protection et de la réalisation du droit des femmes en matière de dépistage du VIH. Les résultats révèlent qu'il

Resumen

Las reformas sanitarias de 2014 en Indonesia abogaron por cobertura universal de salud (CUS) para todas las personas indonesias e incluyeron disposiciones para establecer programas integrados contra el virus de la inmunodeficiencia humana (VIH), con pruebas disponibles en centros de salud comunitarios y hospitales para mujeres embarazadas y mujeres en edad fértil. Sin embargo, aún no se sabe con certeza si las pruebas han sido eficaces. Este artículo se enfoca en las barreras que enfrentan las mujeres para acceder a pruebas de VIH y presenta hallazgos de las experiencias de 18 mujeres VIH-positivas. Para triangular los hallazgos, se realizaron entrevistas con 26 trabajadores de salud, 9 trabajadores de organizaciones no gubernamentales y 12 partes interesadas con relación al VIH. El artículo examina las barreras al acceso de las mujeres embarazadas a pruebas de VIH y muestra que las barreras están relacionadas con la carencia de derechos de salud reproductiva de las mujeres. Se destacan los derechos reproductivos en la Carta para una Atención Materna Respetuosa, y las violaciones señaladas pertinentes a las pruebas de VIH durante el embarazo. Cinco de las violaciones de derechos denunciadas son: las mujeres no pueden acceder a la información; no pueden tomar decisiones informadas; no tienen derecho a confidencialidad y privacidad; sufren discriminación continua; y no tienen derecho a pruebas de VIH oportunas. El incumplimiento de Indonesia de proteger estos derechos contribuye a que se les niegue a las mujeres pruebas de VIH. Los hallazgos muestran la necesidad de incrementar los servicios de pruebas de VIH para mujeres embarazadas y afirman que el personal de salud y formuladores de políticas de programas deben ser considerados responsables de proteger y cumplir los derechos de las mujeres con respecto a las pruebas de VIH. Los hallazgos muestran que los formuladores faut que les décideurs procèdent à des changements pour garantir l'amélioration des services de santé, que les professionnels de santé soient mieux formés et que les contextes socio-culturels et politiques des femmes soient pris en compte.

de políticas deben hacer cambios para garantizar el mejoramiento de los servicios de salud, los profesionales de salud deben estar mejor formados/capacitados y los contextos socioculturales y políticos de las mujeres deben ser considerados.

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