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# Understanding the challenges faced in community-based outreach programs aimed at men who have sex with men in urban Indonesia

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**Abstract.** Background: Community-based outreach programs play an important role in the provision of HIV testing, treatment and health care for men who have sex with men (MSM) in Indonesia. However, qualitative studies of community-based HIV programs have mostly focused on clients rather than on outreach workers (OW). The experiences of MSM peer OW provide insights into how to extend and improve community involvement in HIV programs in Indonesia. **Methods**: This is a qualitative study based on focus group discussions, which brought together MSM OW (n = 14) and healthcare workers (n = 12). This approach facilitated documentation of the challenges associated with community-based outreach programs in Indonesia through a participatory focus group discussion between OW and healthcare workers. **Results**: Findings are reported in relation to challenges experienced in the context of community outreach, and solutions to the challenges faced by OW. It was found that awareness of a shared commitment to delivering HIV programs can facilitate good relationships between OW and healthcare workers. **Conclusion**: Future efforts should consider the role of OW within broader relationships, especially with healthcare workers, when developing community-based responses to HIV testing and treatment. Documenting the role of OW can help contribute to an understanding of ways to adapt HIV programs to reduce barriers to access both for those identified as MSM and others who are ambiguously placed in relation to the programmatic use of such categories.

Additional keywords: discrimination, healthcare workers, online outreach, stigma, transgender.

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# Introduction

The potential contribution of groups most affected by the epidemic to HIV programs has long been recognised in global and regional policy settings. Recently, the role that communities can play in advocacy and contribution to HIV responses and service delivery has been reiterated in global policy, as reflected in the 2016 Declaration to End AIDS issued by the United Nations, which committed to at least 30% of services being community-led by 2030. Although community engagement is framed as one indicator for monitoring the 2016 political declaration, ongoing patterns of criminalisation and marginalisation towards people affected by the epidemic generate diverse forms of stigma and discrimination, despite ample evidence of the benefits that community participation in HIV programs can play. Although community participation in HIV programs can play.

In Indonesia, 25.8% of new HIV infections occurred among men who have sex with men (MSM) in 2017.<sup>5</sup> MSM have been a focus in Indonesia's HIV response, with outreach programs having existed both for them and other key populations for several years.<sup>6,7</sup> This includes outreach programs that follow a peer-based model, in which outreach workers (OW) are recruited from the community they seek to target. Peer-based outreach programs are a common strategy used for hard-to-reach populations, including MSM and transgender women, who may face additional barriers to accessing HIV services.<sup>8,9</sup> Activities undertaken by OW include the distribution of HIV-prevention packages and safe-sex information, and referring individuals to testing, counselling and treatment, often undertaken through existing community-based networks. Although falling

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outside of the commonly accepted scope of their role, OW also assist individuals in navigating health care and commencement of treatment.

Despite these efforts, the performance of outreach programs in Indonesia has been relatively low. 10 This evaluation of success is based on a measure of the number of people targeted for outreach and the number of people who are referred to testing services. 11 By mid-2014, Indonesian HIV programs reported 115 077 MSM tested for HIV, ~11% of the estimated total population of MSM.<sup>12</sup> Moreover, reported rates of testing among MSM have remained poor; according to one survey in 2013, only 24% of MSM said that they had taken a HIV test in the past 12 months. 13 Although such measures are based on quantitative targets, which inform funding mechanisms, it does suggest that increased knowledge about HIV has not resulted in better testing coverage for MSM in Indonesia.<sup>14</sup> Investigation of the complexity of existing outreach programs is needed to both involve and expand community participation in HIV programs in Indonesia in order to improve outcomes.

Despite the role of outreach programs in prevention efforts, the role of OW in HIV programs remains less well understood. In Indonesia, one qualitative study in three cities found that social support from community-based OW played an important role in helping MSM to navigate healthcare systems. 15 Another study found that, from the point of view of transgender women and MSM who access HIV prevention programs, OW acted as a motivation for accessing HIV testing, care and treatment, along with the provision of easy-tounderstand information. The same study also described several possible limitations; including the perception that OW could improve the appearance and delivery of HIVrelated information so that it would be better tailored for specific groups within the community. 10 Although experiences of the subjects of HIV prevention programs are relatively well understood, a recent scoping study did not list any published qualitative research that documents the role of OW in delivering services related to HIV prevention and treatment.<sup>16</sup>

In Indonesia, one barrier to the participation of MSM communities in the national HIV response are documented forms of stigma and discrimination.<sup>17</sup> Although same-sex sexuality is not criminalised in Indonesia, vague and discriminatory laws at various levels are used in ways that make MSM, including peer-based OW, vulnerable to criminal prosecution and harassment. 17,18 We also acknowledge that MSM is a category that - although commonly used by OW in the field - may not always reflect the self-identification or definition of those addressed by it. 19 Although sympathetic to these critiques, among OW and others encountered during our research, MSM (and its Indonesian translation) is used as one term for self-identification. Research focused on MSM OW can contribute to a better understanding of how stigma and discrimination are a barrier to community participation in national responses to HIV in Indonesia. Moreover, it can also help to understand how the categories used in HIV programs and attempts to maintain a clear distinction between them, such as that between MSM and transgender, can themselves become barriers to accessing testing and treatment.

This article presents the results of a qualitative study based on a sample of peer OW for MSM who work for one community-based organisation in Jakarta (n = 14). In order to better understand the experiences of OW for MSM in Indonesia, we developed the following research questions to document the experiences of peer-based OW in HIV programs: 'What are the challenges faced by community-based OW in the provision of HIV services in Jakarta?'; and 'What solutions do OW develop in their work in the community, including partnerships with healthcare workers, to address these challenges?'.

Our research objective was to record challenges faced by self-identified MSM community OW, as well as the solutions that they presented to these challenges in the Indonesian context. Rather than seeing solutions as a specific type of end-goal, we were interested in how OW seek to address the problems that arise in the course of their work, often reflecting significant innovation and reflexivity. This also helped to better understand the activities that OW undertake beyond what is presumed of their role at the policy level. We were particularly interested in understanding the challenges that OW face as they navigate relationships with healthcare workers in a context where stigma and discrimination are commonly cited as barriers to access.<sup>20</sup> In doing so, we aimed to understand how OW worked as part of existing HIV testing and treatment efforts, and what knowledge they possess that may contribute to the development of improved community-based responses for MSM in Indonesia.

#### Methods

Design

The research design for the project was ethnographic, a method of data collection and analysis often included as a component of studies that seek to understand the social and cultural dimensions of HIV in Indonesia.21-24 Following ethnographic conventions, research design comprised the following steps: identification of interest in peer OW for MSM; a preliminary investigation including interviews and an observational component; data collection; and the reporting of results.<sup>25</sup> Ethnographic research allows for a degree of responsiveness to changes in the field.<sup>26</sup> Based on preliminary research with OW in a previous study, we observed that they commonly worked together with healthcare workers. We therefore decided on a participatory method of data collection through focus groups which brought OW and healthcare workers together to work on a shared set of problems.<sup>27</sup> We recorded their interactions in order to obtain an understanding of the ways that they undertake their respective roles, often in a collaborative manner.

The participants in the study were identified through purposive sampling.<sup>28</sup> Based on an existing relationship, the researchers contacted one community-led MSM outreach organisation in Jakarta to describe the project and to invite the recruitment of OW into the study. The director of the organisation then made formal contact with local health clinics with whom they had a working relationship to recruit healthcare workers to voluntarily participate in focus group 354 Sexual Health B. Hegarty et al.

discussions together with OW. All of those currently undertaking either of the two professions, aged  $\geq$ 18 years and able to give informed consent were eligible to participate.

## Data collection

This article is predicated on data collected from four focus group discussions moderated by an experienced Indonesian facilitator and overseen by PI Hegarty, an anthropologist. The use of focus group discussions as part of an ethnographic approach, entailing long-term relationships and observations, allowed us to explore how participants co-created narrative understandings of their own and others' experiences. Focus group discussions also enabled observation of verbal and nonverbal interactions between different participants, including points of disagreement or contention. We brought OW and healthcare workers together as a group so that they could both share their views, as well as to understand how they would interact together. Also We were also interested in tensions and contestations over authority between the two groups.

Based on an approach adapted from human-centred design, the research team developed focus group discussion guides based on participatory problem-solving exercises with input from the local facilitator. <sup>27,33</sup> Focus group discussions were semi-structured and broken up into three distinct sessions. First, we asked participants to identify challenges experienced in outreach together, guided by the following themes: (1) at the community level; (2) at the healthcare clinic (either during testing or access to medication); and (3) within broader society and policy settings. We also asked participants to further drill down on challenges according to: (1) digital spaces; (2) physical spaces; and (3) the clinic. Second, in groups separated according to roles, participants responded to this list of challenges to outreach work, and recorded responses and prospective solutions. Third, we discussed all challenges and responses during a final discussion of shared challenges and solutions identified, inviting participants to reflect on points of continuity or difference discovered in the process.

#### Analysis

The focus group data were recorded and transcribed in Indonesian. Analysis of transcripts drew on a grounded theory approach as a means to provide guidance on the data, <sup>34</sup> followed by a thematic analysis. The team focused on comments related to a specific question or comments that provided a detailed example of the challenges faced by OW. Team members reviewed the Indonesian transcripts, examined the most frequent and outstanding comments related to the research questions and coded transcripts for themes. <sup>35</sup> Similar themes were grouped together using a 'cut-and-paste' technique. <sup>36</sup> Findings presented in this article highlight the themes related to the challenges faced by OW in the context of their work and the strategies that they use to overcome them.

## **Ethics**

Ethics approval for the study was granted by the University of Melbourne (1852983.1) and Atma Jaya University (0671/III/LPPM-PM.10.05/06/2019) Human Research Ethics Committees. Using a participant information sheet and a

consent form, translated into Indonesian, each participant consented to voluntary participation in the meeting and use of the data. Participants were provided with information about avenues for local counselling support. All identifying information of organisations and individuals is removed from this article, and pseudonyms are allocated to each response to ensure confidentiality. Participants were offered IDR 125 000 per day over 2 days for their time (approximately AUD12), an amount selected on the basis of average costs of return transport to the focus group venue and compensation for time spent outside of work.

#### Results

Challenges faced when conducting HIV outreach for MSM Declining public 'hotspots'

OW described the difficulty of locating MSM, given declining physical 'hotspots,' the public settings where MSM frequently congregate. OW identified that some MSM would actively avoid OW in public settings, even when they shared a common community or understanding of self-identification. The reasons for this were due to a range of social and cultural factors. OW described how they had observed a decline in the number and density of hotspots in the past few years. They identified several reasons, including fear of increased discrimination towards MSM in public and an increasing use of online applications to find partners for sex.

'In the past, we used to gather together, and usually we'd be visible because we'd gather in one location in a mall for instance, we'd often see that. And you could break it down, because you'd be able to identify MSM of different ages. But now it is different, these places are very empty.' (OW 1)

OW described that the fear of criminalisation had affected community engagement at hotspots. OW speculated that this had led to an increase in the perception of stigma from the general public towards the MSM community. This was accompanied by a fear among MSM of police raids on existing hotspots. OW described that this decrease in physical locations where MSM gather made outreach activities more difficult.

'For MSM, the hotspots have been affected by recent 'LGBT issues' developing in Indonesia. The term MSM has itself become a stigmatising term. The hotspots that used to be available for preventing HIV in the past no longer exist. The places where the community used to hang out are difficult. So, it was better in the past. It was better in the past for us OW as well.' (OW 2)

In some cases, OW described an increased difficulty in accessing commercial venues, such as nightclubs and malls. They described how the management of venues were increasingly reluctant to provide permission for OW to enter to distribute information or provide voluntary counselling and testing together with local healthcare workers.

'What I would like to emphasise is the permission that we need [to enter hotspots]. We had a hotspot in the city,

the name is [nightclub name]. It is exclusively visited by the MSM community. It has become difficult for us to undertake mobile voluntary counselling and testing (VCT) there. We needed to have a contact on the inside, who works in the club. We were able to enter, but approaching the owner of the nightclub was very difficult. A few times we requested through the recommendation of the Department of Tourism, to create a way for us to conduct the VCT. And we encountered a lot of [HIV] cases there in the community. And there's another one, [nightclub name] which required a lot of effort to get into as well. And again, at those two locations it has become even more difficult yet. Maybe the permission has become difficult to obtain because other locations are closing. Or maybe it is the government, or some politics from the outside, which means that in the end those locations overlook the threat [of HIV] to the community.' (OW 3)

# Difficulties in discussing HIV during outreach

OW described that MSM were rarely interested in learning about HIV through biomedical or behavioural forms of scientific expertise. OW shared stories about the difficulties of their task in a context where discrimination towards MSM intersected with that experienced by people living with HIV. As a result, OW expressed how they struggled to correct what they understood as misconceptions about HIV within the community.

'If we look outside of the context of [inner city suburb]. The clients there are very much part of the community. But they don't want to consider HIV at all. So even confirming whether they are well or unwell, it is difficult. In their mind HIV and AIDS is the same. But of course, these are different things.' (OW 4)

OW also explained their frustration in conducting outreach work when the community seemed so reluctant to engage with them in terms of what they framed as 'accurate knowledge'. They framed this perceived accuracy in terms of its scientific validity. How and in what ways OW dealt with what they understood as a proliferation of incorrect knowledge among the community, and a lack of willingness to engage with them, emerged as key topics of concern. Referring to drastic measures, one participant sought to convey the risk of HIV to the community; he described deploying what he called forms of 'shock therapy' as one necessary tactic. This strategy referred to describing the effects of an untreated HIV diagnosis in a deliberately confronting way.

'Because there are actually MSM community members who are young and difficult [to conduct outreach for]. Sometimes they won't accept more subtle information, even if we express our frustration. So we sometimes say harsh things, like, 'It's like this, do you want to die? If you want to die, we'll just bury you. Think of your family.' It's a form of shock therapy. We cannot only provide information in a gentle way, but we sometimes

need to give them more gruesome information about HIV.' (OW 5)

Solutions to challenges in the provision of outreach

Providing online outreach

In light of declining physical hotpots, OW persistently attempted to get in direct contact with members of the community. They most often described using online methods for educating the community about HIV. OW described online outreach as a necessary but time-consuming task of which the success was difficult to measure. In each focus group discussion, OW shared approaches that worked and those which did not for outreach activities towards MSM on social media.

'I don't just message MSM on Whatsapp once a day, you see. I do it two times a day or more. I will follow up once, twice, and again and again right up until I am blocked, which happens often. Even then I will still try to contact the person.' (OW 6)

Another OW similarly described their challenge in terms of a disconnect between their task of providing information about HIV and lack of interest from the intended audience. This challenge remained the case whether outreach was undertaken in physical hotpots or through online applications. One solution engaged by OW in online contexts was to combine information about HIV with attractive images — including those of attractive bodies — which solicited a more enthusiastic response.

'Providing information is very difficult. Take the example of providing information about HIV on Facebook. It is rare that anyone likes it, or comments on it. It is quiet online. But if we post something, like our bodies, our faces, or something like that. We will get lots of response, a flood of responses to our Facebook message inbox.' (OW 7)

Assisting MSM to navigate stigma

OW frequently went beyond their commonly understood activities, playing diverse roles in helping MSM to access HIV testing and treatment. This did not only include practical matters, such as attending appointments and taking medication, but included assisting MSM to navigate the barriers associated with experiences of stigma. OW described taking a pragmatic approach to help clients to avoid forms of stigma as they navigated testing and treatment.

OW responded to forms of stigma with strategies that reflected an understanding that stigma emerged from an individual's inappropriate appearances in a given setting, which commonly reflected their gender or sexual identity. Common strategies described included encouraging MSM to 'fit in' with their surroundings where their appearances attracted unwanted attention. This was particularly relevant to individuals whom OW identified as 'transgender' on the basis of gender presentation, but who self-identified as MSM. This distinction was one that OW reflected upon as key to experiences of stigma in the clinic. One OW recalled

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an encounter with an MSM who regularly wore women's makeup.

'I have an experience of bringing one MSM to take a test. This person is actually an MSM but they are more comfortable wearing makeup. But they don't have long hair or wear a wig. And I asked, 'Are you a transgender woman or an MSM?' They answered, 'I am an MSM.' It was like that.' (OW 8)

This OW provided an account of how they had counselled the MSM to try to adjust their appearances.

'So I tried to explain before they went into the clinic, so that they could avoid stigma. 'Next time, you'll have to encounter other community members here. If you can, I suggest that you don't dress like that.' They responded, 'I'm comfortable like this.' I answered that this is no problem, if it has happened on this day, it is OK.' (OW 8)

As a result, this person subsequently adjusted their presentation to better align with the expected norm of what an MSM 'looks like' or appears when accessing HIV services (i.e., a normative masculine gender presentation). Rather than offer this as a success story, however, this OW articulated that this experience resulted in substantial discomfort.

OW also suggested that there could be a significant difference in the accepted range of gender presentation among clients according to the clinic and even time of day. In the case of clients who had a more feminine gender presentation, they accompanied them to clinics which were more familiar with diverse gender expressions, or during quieter times of the day. This latter effort meant that they attracted less attention from other patients when navigating the clinic.

'Sometimes I offer a solution like this. There are clinics that are quieter, or are used to diverse gender expressions. So I say, what if we go to Monday [to clinic A] without us having to have an audience? Or, although another clinic is further away, because there are many transgender women there you won't face the stigma that you would [at clinic A]. So there are some possible solutions.' (OW 9)

In both cases, a demand to fit in was shaped by imagined social and cultural norms related to gender presentation and class, as well as invoked understandings that reflected a degree of permeability or ambiguity between the categories for MSM and transgender in particular. It appears that the burden of 'reducing stigma' is widely understood to be borne by individual clients themselves, with OW playing a role in disciplining the appearances of their MSM and transgender clients to attain standards of dress and presentation imagined as fitting both with those categories, as well as with the expectations of other patients and staff in clinics. Insisting on a particular gender presentation to avoid attention in the clinic may suggest that OW can, in certain cases, participate in what could be conceptualised as structural forms of stigma. Yet, although this speaks to the need to improve Indonesian

clinics so that they are more accommodating to MSM and transgender clients, it also suggests a need to better understood how these forms of stigma are reinforced by the categories used in HIV policy and programs.

#### Discussion

This study examined the experiences of community-based OW for MSM and healthcare workers in urban Indonesia. There are several limitations to this study. In particular, although we collected data from OW and healthcare workers, we have only included data from OW here, given the focus of this paper on the role of the community in HIV programs. A focus on the experiences of healthcare workers in working with OW would offer further insights into community participation in HIV programs. Moreover, all participants were recruited through one organisation in Jakarta. The fact that these OW and healthcare workers have a relatively good working relationship may not be representative of the situation in Indonesia more broadly. Lastly, despite the fact that 'MSM' and 'transgender' are categories that are understood to be made up of distinct communities with different needs, in certain cases, there appears to be an overlap or ambiguity in affiliation. A focus on transgender peer-based OW would add further complexity and nuance to this account. Despite these limitations, to our knowledge, this is the first qualitative study to record the experiences of MSM peer-based OW in Indonesia. This enhances understandings of community-based approaches to HIV programs. It thus helps to understand the shifting roles played by OW and provide directions for ways to improve the community response to HIV in Indonesia.

Our study highlights that Indonesia is a challenging place to undertake peer-based HIV outreach activities for MSM. Nevertheless, OW described positive engagements with healthcare workers as one way that outreach work did not stand alone from, but within a broader system aimed at providing HIV care. Our findings build on other research findings that document factors influencing access to HIV care among MSM, attending to the role that OW play in Indonesia's HIV response. 10,15 It suggests the possibility not only for partnerships between healthcare workers and the community, but also for a crossover in personnel. It suggests that the MSM community is capable of participating in the Indonesian HIV response in more diverse capacities than only in the roles commonly associated with OW.

In this respect, this study contributes to an international literature that show the need for expanding a commitment to community-based responses to HIV. 4,38 In doing so, it builds on a number of studies undertaken in several Asian contexts that illustrate the need for recognising the centrality of community responses to HIV. 39,40 This includes advocacy and an expanded role of the MSM community in defining HIV policy. This also includes the role the community can play in the training of healthcare workers. 41,42 One of the biggest challenges in effective engagement with HIV care among MSM is a shortage of evidence about the role that they currently play in the HIV response; including as OW, community advocates and healthcare providers. 38 The findings

of this study address a gap in research in Indonesia on issues pertaining to structural and cultural barriers that affect access to HIV care for MSM.

Our research presents several avenues for future research to increase the evidence base for understanding the role of the MSM community in HIV programs in Indonesia. There is a need to document the changing role of OW, including the strategies that they draw on to provide HIV care. This is important given increasing calls at the international policy level for the community to adopt new forms of treatment and prevention, particularly through HIV self-testing. 43 Recent qualitative evidence focused on MSM in Indonesia suggests that stigma from healthcare workers makes self-testing an attractive option.<sup>20</sup> However, our study, in bringing together the views of OW in interaction with healthcare workers. suggests that stigma is not only experienced at the individual level but is produced through policies and programs. This extends to both the categorisation of individuals as 'MSM' and the kinds of individuals who are imagined to 'fit in' in clinics.

The efforts described by participants to limit the effects of stigma through attending to individual's appearances suggests the importance of considering the social and structural sources of stigma that are experienced by MSM and transgender communities. For example, the efforts of OW to assist MSM to avoid stigma reflect one way that the programmatic use of the category MSM can operate as a barrier in the provision of HIV testing and treatment. Efforts to expand community involvement in HIV policy making, including proposals for self-testing, should also consider the ways that stigma has been shaped by structural concerns of access and policy rather than factors related to the beliefs of individual healthcare workers.

# Conclusion

Our study highlights the important role that OW play in developing community responses to HIV. To date, there are very few qualitative studies that document the experiences of OW in existing HIV programs. This existing role, and the fact that OW undertake community engagement in a setting where those identified as MSM experience stigma, makes this an important area for further research. In particular, the role that OW play in building relationships between healthcare workers and the MSM community could provide methods to improve the quality of outreach programs. OW are also well placed to assist HIV programs to consider incorporating understandings of gender and sexual cultures within the community when considering community-based HIV programs. Drawing on their experience helps to consider how cultures of HIV prevention, and categorical distinctions used therein, can themselves become structural sources of stigma and barriers to accessing care. Thus, this study presents a starting point to better understand how, through funded outreach programs for MSM, the community is actively contributing to national HIV programs and the barriers that they face in doing so.

# **Conflicts of interest**

The authors declare no conflicts of interest.

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