The Biosocial Body: HIV Visibility in an Age of Pharmaceutical Treatment in Indonesia

Peer outreach workers play a pivotal role in assisting HIV positive people to access pharmaceutical treatment. In their role mediating between everyday sexual cultures and biomedical knowledge, outreach workers for MSM in Indonesia’s capital city emphasize the need to manage the visibility of the HIV positive body as it appears to others. In order to enter clinical spaces, clients must adopt neat attire, strive to embody a physique that is robust, and maintain a clear skin tone. Clients must also learn to gain mastery over their gender performance as a revelation of their sexuality. Drawing on an understanding of personhood in which individual sexual and HIV positive status can be either “open” or “closed,” outreach workers interpreted the self-responsibility required to remain in treatment not in terms of inner subjectivity but outer appearances. Attending to these paradigms of visibility reveals the social relations necessary for accessing treatment.

Key words
HIV, Indonesia, the self, visibility, sexuality

Main body of the manuscript
One afternoon in late 2017, I watched a 21-year-old man step from a small blue minibus into the dust and noise of a road in front of a large hospital in Jakarta, the sprawling capital city of Indonesia with a population of approximately 10 million people. This man, who I call Raja, had tested positive for HIV at a mobile voluntary counselling and testing service at a nightclub in the city the previous week.

This is the author manuscript accepted for publication and has undergone full peer review but has not been through the copyediting, typesetting, pagination and proofreading process, which may lead to differences between this version and the Version of Record. Please cite this article as doi: 10.1111/etho.12325.org.

This article is protected by copyright. All rights reserved.
These testing services were run by local health clinics and attended by a peer-based outreach program (penjangkauan) of a non-governmental (NGO) for men who have sex with men (MSM). MSM, translated into Indonesian as lelaki berhubungan seks dengan lelaki (LSL), is a category used in both policy domain and in everyday life in my fieldsites to refer to both a population of people and individuals who share a behavioral profile of sexual practices with other men. Upon discovering that he had tested positive for HIV, Raja asked an outreach worker, those who undertake a wide range of paid activities to educate and guide people within their own community, what he was to do. Given that treatment was not available at the nightclub due to the requirements of Indonesian health bureaucracy and because Raja was required to undertake a range of tests beforehand, he would have to attend a clinic or hospital. The outreach worker and I took Raja’s details and arranged to meet him at a hospital where he would be able to commence lifesaving anti-retroviral treatment.

The following week the outreach workers and I met Raja outside the hospital and entered the building together. As in many hospitals in Indonesia, the HIV clinic was both separate and apart, hidden in a discrete corner at the rear of the building. Entry to it involved passing through a maze of crowded rooms and corridors, requiring either coming with someone who had been there before or asking for directions along the way, which would lead to awkward exchanges. We finally arrived at an innocuous door, with a small sign inscribed with the name of the clinic, which contained neither the word HIV nor AIDS. Located opposite a crowded food court and row of bank machines, the clinic’s placement reflected the ambiguity of HIV programs within the Indonesian national health system. This obscurity emerged in different guises as we accompanied Raja through the tedious bureaucratic processes that consumed an entire afternoon. Throughout, he encountered consistent, intersecting demands that he disclose his status as both HIV positive and an MSM so that he could receive treatment. This disclosure emerged not only in the form of narratives, but in the requirement that he recognize and adjust his visibility to others as an HIV positive person. This reinforced the role of a reflexively practiced visibility, one in which Raja saw his body and appearance as needing to be managed as a prerequisite for commencing treatment.

Through experiences such as these, through which people like Raja discover and learn to contend with their overlapping status as HIV positive and as part of a “key population” of MSM, disclosure is experienced as an embodied visibility which arises through social interaction. During my participation in Bergembira’s activities, I found that rather than an individualized form of discipline focused on the inner self, outreach workers played a crucial role in inculcating in the HIV positive person the art of interpreting and managing their own physical and embodied appearances as they appeared to others. This was particularly the case in light of a growing emphasis on testing and treatment as the demonstrable end goals of HIV outreach. Outreach workers played an important role in translating the global biomedical and epidemiological knowledge contained in international HIV programs into vernacular terms and practices that made sense to young men in Jakarta’s everyday sexual worlds.

I interpret the relationship between young men like Raja and Bergembira’s outreach workers as a form of biosociality, a term that anthropologists use to refer to the kinds of social bonds and desires for recognition forged by patient support groups and shared experience of access to pharmaceutical treatment regimens for a range of diseases (Petryna 2013; Rabinow 1996; Rose and Novas 2005). As Nikolas Rose and Carlos Novas write, the collectives organized around biomedical classifications and
treatments, “often involve quite specialized scientific and medical knowledge of one’s condition” and shape “new ways of making citizenship by incorporation into communities linked electronically” (Rose and Novas 2005, 442). Beyond the domain of information and knowledge about disease and its treatment, however, biosociality is also remaking persons through the management of the body and its appearance to others. The forms of biosociality possible in the context of HIV and AIDS, ranging from patient groups to citizen science (Epstein 1996), has been refigured through the rapid expansion of testing and treatment and their paramount position in global efforts to address the global epidemic since the 2000s (Lloyd 2018; Persson et al. 2016). As Paparini and Rhodes observe, the prioritization of anti-retroviral treatment has become a “clear pathway to HIV biological citizenship, with viral suppression projected as the objective measurement of success and hope of HIV citizens” (Paparini and Rhodes 2016, 513). Viral suppression, wherein the virus is no longer detectable in a person’s blood and hence cannot be transmitted to others, serves as a measure of progress towards both the population level goal of the “end of AIDS” and as an ethical imperative for the individual person living with HIV. In this context, the visibility of the body of the HIV positive person, particularly those who are ill because they have not accessed treatment in a timely way, has become a specific problem to be managed.

Rather than only a form of discipline undertaken by the HIV positive person, peer outreach workers discipline the biosocial body in an age of pharmaceutical treatment. Corresponding with anthropological efforts to understand how biosociality operates within specific social and cultural worlds (Marsland 2012), I show how outreach workers’ close attention to the invisibility and visibility of the bodies of HIV positive MSM exposed patterns of exclusion most acutely experienced by clients whose appearances made them hard to hide. This was particularly pronounced in an Indonesian context where the visibility of the body is a key explanatory trope in understandings of HIV and its treatment (Boellstorff 2009; Samuels 2020; 2016). Focusing on outreach workers’ management of biosocial bodies helps to understand how cultural paradigms of visibility map onto social relations which enable access to pharmaceutical treatment. The tools for addressing the HIV epidemic were poorly correlated for those who struggled to become invisible, as was the case for Raja, a poor, gender nonconforming and visibly unwell HIV positive person.

I investigate the links between disclosure, visibility and understandings of the self in an age of widespread treatment by attending to the social relationships forged between HIV peer outreach workers for MSM and their clients. I draw on ethnographic fieldwork conducted since 2017 with one outreach organization that I call Bergembira. The research on which this article is based took place over approximately four months of participant observation during annual visits made to Indonesia between 2017 and 2019 as part of an ongoing collaborative ethnographic project with epidemiologists and physicians about peer-based outreach work and support groups for MSM (Hegarty et al. 2021; Hegarty, Nanwani, and Praptoraharjo 2020). My anthropological engagement is thus oriented towards and takes place in collaboration with Indonesian researchers and activists invested in understanding the impact of health inequities on MSM and waria, an Indonesian transgender population (see Mallay et al. 2021). Research consisted of accompanying outreach workers during activities in a range of sites, including at Bergembira’s offices, outreach sites or “hotpots” in Jakarta, and assisting clients to access clinics. Outreach organizations, organized into and reflecting a community, are crucial nodes which connect HIV positive people to one another and to pharmaceutical and social recognition.

This article is protected by copyright. All rights reserved.
Rather than neutral, outreach workers’ negotiation with the visibility of the biosocial body highlighted inequalities in access to HIV testing and treatment as they emerged within everyday social worlds.

**Looking neat and appearing well**

Although responses to HIV in Indonesia have shifted considerably over the past decades, since the mid-2000s, the country has made considerable efforts to expand access to testing and treatment with enhanced support from international funding agencies. These include the Global Fund and the U.S. President’s Plan for AIDS Relief (PEPFAR), both of which fund a range of programs broadly focused on increasing access to HIV testing and anti-retroviral therapy uptake and adherence. Accompanying this funding has been a shift away from more autonomous community-based outreach work focused on prevention and locally translated safe-sex messages, towards a greater integration into systems that are focused on testing and treatment. In line with the imperatives of global programs, outreach programs target the “key populations” assessed to be at greater epidemiological risk of contracting HIV. This includes populations grouped into categories MSM, transgender, female sex workers and injecting drug users. Estimates based on Indonesian national surveillance data have indicated that as many as one third of all counted as part of populations of MSM in several major Indonesian cities are living with HIV, and that a significant proportion of those who test positive do not access treatment despite increased availability of both treatment and knowledge. Despite the increased availability of testing and treatment for HIV, however, the fact that many of those eligible either do not enroll in treatment or cease treatment after a time is a concern to which outreach workers are increasingly asked to direct their attention.

As is the case globally, Indonesia has adopted a policy framework which has accompanied the widespread availability of effective anti-retroviral medications. In 2019, the Indonesian Ministry of Health introduced a policy that HIV services, encompassing testing, adequate diagnostic facilities, and anti-retroviral medications be made available at all local, government-funded healthcare clinics (Lazuardi 2019, 2). Although in reality access to treatment is hampered by a range of factors, including shortages of medication, bureaucratic complexity, a lack of trained medical staff, and the risk of having one’s diagnosis exposed (Butt 2011; Lazuardi 2019), from a policy perspective, HIV positive patients are imagined to move seamlessly though a “cascade of care” from diagnosis to treatment (for a critique at the global policy level, see Nguyen et al. 2011). The prioritization of testing and treatment in HIV programs has reshaped the work that peer outreach workers perform. They are increasingly focused not on providing information, but on ensuring adherence to medication and an undetectable viral load. In Indonesia, a high CD4 count (a laboratory blood test the presence of white blood cells which serve as an indication of a healthy immune system) often serves as a proxy for an undetectable viral load due to limited laboratory services. In this setting, outreach workers work as brokers between the social and biomedical aspects of treatment and prevention, ensuring that HIV positive individuals enroll and remain in treatment and undertake routine laboratory tests. A significant proportion of outreach work is now concerned with closely monitoring patients to ensure that they test, treat and remain connected to pharmaceutical and diagnostic systems.

Bergembira is one of several funded outreach programs whose primary objective is to support clients to access HIV testing and treatment that is usually available at primary healthcare clinics. Although there is a degree of heterogeneity, the programs undertaken by non-governmental organizations such
as Bergembira have increasingly focused on “hard to reach” key populations, who are at both a higher risk of contracting HIV and who are more likely to be “lost to follow up” or test positive and subsequently cease to take treatment (for accounts of programs for MSM and transgender women in Indonesia, see Lazuardi et al. 2019; Nugroho et al. 2019). Given that HIV infection is life-long and requires anti-retroviral medication administered consistently to prevent a weakened immune system and subsequent infection, a significant proportion of outreach work involves closely attending to those with a positive diagnosis to make sure that they are retained in treatment. This model assumes that, with the availability of widespread anti-retroviral therapy, HIV positive people are increasingly “invisible,” as the virus is transformed into a subjective experience likened to a chronic illness that can be managed through pharmaceutical treatment (Moyer and Hardon 2014). This shift from the visibility of AIDS to the invisibility of HIV is reflected in shifts in terms used in programs. The former widely used Indonesian term for HIV positive people, “person living with AIDS” (orang hidup dengan AIDS), has only recently been substituted for “person living with HIV” (orang hidup dengan HIV (ODHIV)) in official circles for the reason that the older term was associated with the visible illness of AIDS. These shifts in knowledge, marked by treatment as a pathway to biological citizenship, were also experienced as a shift in the meanings of the individual body of the HIV positive person. Talk of invisibility at the policy level was undermined by the ongoing presence of the many HIV positive people who failed to undertake routine testing and, as a result, only presented themselves to outreach workers and clinics when they showed physical symptoms of disease.

Although the role of outreach workers incorporated a wide range of technocratic tasks tied to policy imperatives, an everyday practice that outreach workers saw as central to their work was focused on visibility and bodily comportment of HIV positive individuals. This included various forms of guidance that extended well beyond that included in official policy guidelines, incorporating skincare, weight gain, hair treatment and the timing of meals and medication. In discussions with their clients, outreach workers described dark skin and low weight as physical appearances to be avoided, with an ideal of “healthy” (sehat) or “clean” (bersih) equated with skin and eyes that were “white and clear” (putih dan bening) and a “well-fed” (gemuk) body. Dressing neatly, eating three meals per day and consuming medication at a precise hour of the day was presented as an embodied form of discipline which had the aim of appearing well in the eyes of others. This attention to the body and appearances of HIV positive young men was particularly urgent for those who presented with symptoms of illnesses like tuberculosis. One experienced outreach worker explained that he was so well versed in recognizing the visual signs of HIV that he could identify it based on scrutinizing the appearance of a person’s face and mouth. In describing the challenges of their role, Bergembira outreach workers described how up to half of all their patients presented with such symptoms, which they reflected was because those who did not have symptoms either thought they were fine or preferred not to know. MSM were captured in a paradox of visibility; they sought testing only if they displayed symptoms, while the visibility associated with symptoms meant that they occupied a marginal position according to a framework in which living with HIV meant being invisible.

While common, Raja’s visibly dark skin, lethargy, and weight loss did not align with normative expectations. Indeed, Raja had conceded to outreach workers that he had received a positive diagnosis for HIV months prior but had failed to enroll in treatment for reasons that were not entirely apparent. In preparation for his visit to the hospital, as they usually did in cases where clients presented with
symptoms or were nonconforming in some way, outreach workers provided Raja with stern instructions to present himself as neatly and as well as he could.

As if to ward off against the effects of his unwell physical appearance, on his visit to the hospital on the day that we met, Raja carefully followed the instructions given by his outreach worker. He dressed immaculately, adhering to the standards that outreach workers referred to as “neat” (rapit), including a button-up shirt, clean jeans, and quality shoes. Raja also fastidiously avoided slipping into the overtly feminizing forms of speech and bodily comportment that were his usual habitus. He undertook a concerted effort to discipline his body to appear “normal” to others. This invisibility was consistently challenged in the face of repeated demands from medical and outreach staff that he disclose his status as an HIV positive person and an MSM in order to commence treatment. For example, immediately upon entering the clinic, the nurses at the registration desk asked whether Raja had received a test result. In full view of the clinic waiting room, they probed him about whether his previous test result had returned positive or negative. Later, when we met with the doctor, she asked him to recognize that sex with men placed him at risk and therefore that he should avoid it. At each of these moments, Raja was trained to anticipate and navigate his position in an exchange of gazes, in that he was both visible to others and aware of the potential effects of that visibility on him.

Individuals such as Raja, who moved in and out of the steps of the “cascade of care” in a non-linear fashion and thus failed to become invisible, posed a problem for organizations like Bergembira. In order to receive funding for a given month and in turn to ascertain their funding in future, outreach workers at Bergembira were required to increase the number of HIV positive people either retained or newly enrolled in treatment. The overall aim was to reduce the number of people “lost to follow up” in a given period, reflected in elaborate efforts to undertake monitoring and evaluation in HIV programs form part of a wider emphasis in global development on what Sally Engle Merry “the magic of numbers and the appearance of certainty and objectivity that they convey” (Merry 2011, S84). To be eligible for funding, outreach workers had to ascertain and record a person as an MSM, was diagnosed as HIV positive, and enrolled in anti-retroviral treatment. The expansion of funding had given rise to competing organizations, with separate groups of outreach workers for each key population. Outreach workers engaged actively with the political economy of HIV programs, within which they saw the person living with HIV as necessary for receiving funding. Rather than a straightforward process of documenting facts in the field, outreach workers engaged with practices of making their target populations visible as they appeared to them in the social worlds within which HIV outreach took place.

Partially given the political economy of HIV funding, wherein the allocation of resources was tied to identifying new clients and demonstrating overall increases in rates of testing and treatment, outreach workers expended considerable effort seeking out MSM who were more likely to test positive for HIV. The Bergembira office had large maps displayed of sections of the city which were color-coded as red, yellow and green, representing the number of people testing positive and negative in a given locations. Green sites would be quickly abandoned, with more resources and personnel transferred to red and new sites where a potentially higher number of cases might be found. Corresponding with this effort, outreach workers cultivated social methods through which to read the body for signs of what they described as “MSM-ness” (ke-LSL-an), in addition to a higher likelihood of a positive HIV
diagnosis. A concern for the visibility of MSM extended well before clients set foot in a clinic, shaping how outreach workers ascertained who their target population was and how they should best approach them. Upon locating MSM, outreach workers then worked to manage their visibility as they navigated access to testing and treatment. From their first encounter in the field through to their ongoing efforts to retain them in treatment, outreach workers shaped what it was to be seen as an HIV positive person and as an MSM within distinctive paradigms of visibility.

Paradigms of visibility: “open” and “closed”

Raja first became visible to outreach workers amidst the noise of a mobile testing site at a nightclub in the early hours of a Sunday morning. These mobile testing sites, run in collaboration with local clinics, offered an opportunity to both increase testing rates and to capture populations who were unlikely to attend a clinic. The outreach workers I accompanied were exhausted and, having approached their target of tests conducted for the night, were busy packing up their information booth. Hovering nearby was Raja, and we soon started talking about how he had come to Jakarta and the challenges of life in a metropolitan environment with a high cost of living and a lack of stable employment. Raja was initially visible to outreach workers because they recognize him on terms that they recognized as visibly gay and hence clearly recognizable as part of a population of MSM.

To Bergembira’s outreach workers, Raja represented an illustrative case of an individual who had been “lost to follow up,” precisely the scenario that they aimed to avoid. Although Jakarta supposedly has well-stocked clinics and widely available HIV outreach programs, outreach workers conceded that obtaining access to treatment in practice was rarely as smooth as it was presented in official narratives. Rather than concentrating on structural concerns of access, outreach workers postulated that Raja had failed to access treatment due his failure to “accept his status as an HIV positive person” (menerima diri sebagai orang hidup dengan HIV) they would struggle to continue in treatment. Rather than framing their work solely in technocratic terms tied to metrics, peer outreach workers navigated the field through such social encounters, shaped by who became visible to them in what settings. Bergembira peer outreach workers played an important role in adopting and translating a competing understanding of visibility related to sexuality and HIV status to craft what they referred to as the “self” (diri). This was not an individual self, therefore, but one that was framed as influenced by the gaze of other people as they moved through the spaces in which they accessed testing and treatment.

As outreach workers interpreted cases like Raja in terms of a failure of acceptance, they described the self by using the idiom of being “open” (buka) and “closed” (tutup). Outreach workers emphasized that HIV positive people needed to “open their status” (buka status) to themselves, outreach workers and medical staff, rather than “be closed” (tertutup). “Lost to follow up” was thus interpreted as one consequence of remaining “closed,” which corresponded with a lack of willingness to acknowledge an HIV diagnosis even at the level of the self. The use of this pair of concepts predates their relationship to HIV programs, and appears to have migrated out of the common use of “open” and “closed” as a pair of terms used to refer to the relationship between embodied practices and sexuality (Boellstorff 2005). Interpreting the centrality of states of being “open” and “closed” to gay sexuality in Indonesia, Tom Boellstorff referred to this paradigm of visibility as, “a ‘style’ deployed and managed, something that can even slip from control and manifest itself out of place, like work or at

This article is protected by copyright. All rights reserved.
home” (2005, 171). The most common style through which a gay person became “open” was the performance of femininity on the male body known as ngondhek (Boellstorff 2005, 166). Rather than the deep interiority of the confessional model of the self (Foucault 1978), sexuality in Indonesia reflects widespread patterns of personhood in Southeast Asia in which appearances can betray one’s inner state (Errington 1989). A model of the self that Unni Wikan (1990, 262) has called “to be, and feel, perpetually exposed” was reflected among Bergembira’s outreach workers, who understood a person’s HIV positive status as able to be betrayed to a public audience by a simple slip in outer appearances.

In the course of everyday work, outreach workers considered the femininity on the male body referred to as ngondhek as a primary marker that a person belonged to a population of MSM. However, the visibility associated with ngondhek also demanded caution, given that it could become an unwanted form of visibility in public settings. One outreach worker vented to me that he had brought a client into a clinic where they had to pass by a large window which opened to a crowded waiting room. Upon passing the window, this client momentarily lapsed into a ngondhek performance in an attempt at humor which drew not laughter but glares from those in the waiting room. The outreach worker explained his approach to such behavior as drawing public recognition to the transgression and addressing the client to invoke a sense of shame, “I will tell everyone to look at him. Do you feel weird? If you feel weird, well don’t be angry at us, because you made this problem yourself.” The challenges of managing the visibility of clients were complicated in the case of those MSM who were described as on boundary of belonging to the Indonesian transgender population known as waria (Hegarty 2018; 2017; 2022). Although such cases were common, they jarred with a programmatic and funding distinction made between populations defined as “transgender” and “MSM.” Such cases were often narrated in terms of moments when the visibility of a client contradicted normative expectations in a given space. As one outreach worker recalled, “yesterday my client was not a waria [but dressed in male clothing], but today they dress in a pink shirt. This client was quite conspicuous in the registration room. The security guard whistled!” In both cases, the femininity of waria and of MSM was framed in terms that Gayatri Reddy (2005, 259) has called “public purveyors of stigma,” a negative form of visibility in the clinic that could attract unwanted attention. Although acceptable in limited spaces as a practice that was helpful in defining membership to a “key population,” when performed for a more public audience, both ngondhek and waria visibility could become sources of judgement and condemnation.

Rather than understanding these responses as reflecting a broadly intolerant environment, outreach workers drew on an explanatory trope of “self-stigma” (stigma diri) to interpret these experiences. Self-stigma was a state that emerged when the HIV positive person had failed to “accept their status.” Although people living with HIV do navigate complex considerations around disclosure in Indonesia, and face profound discrimination, the understanding of “stigma” as commonly used among the Bergembira outreach workers reflected its common use in the context of international HIV programs. In HIV policy and research, “stigma” is a common explanation used to interpret the failure of the individual to engage with testing and treatment (Parker and Aggleton 2003). Although the overreliance on the concept has been widely criticized for concealing economic and other social forms of inequality (Castro and Farmer 2005; Wood and Lambert 2008), “stigma” also filtered through to outreach workers’ discussions of their clients’ psychological and social interactions, taking on novel...
formulations and explanatory purchase nevertheless at the level of the self. “Self-stigma” was used here to interpret the behavior of clients who, due to feminine comportment or illness, were visible to others. In this way, outreach workers drew on a concept of the self that was not premised on the subjective life of the individual, but on the visibility of the body in social interaction.

In combating what they called “self-stigma” and the negative forms of embodied visibility that it caused, outreach workers spoke of the need for clients to increase their “self-confidence” (percaya diri). In order to attain confidence, clients should “adjust themselves” (menyesuaikan diri) with their surrounds, working together with outreach workers and other experts to cultivate their bodies in ways that demonstrated greater control. As the above expressions suggest, outreach worker’s use of “self-stigma” emerged together with many concepts related to “the self” (diri) in Indonesia, encompassing percaya diri (self-confidence), tahu diri (self-knowledge), konsep diri (concept of the self), buka diri (open the self) and menerima diri (accept the self). Despite their individualizing overtones, as the experiences of navigating HIV programs suggests, this was a self that emerged in interaction, with a particular emphasis on appearances. This understanding was at play when outreach workers stressed that outreach workers could conceal their HIV positive status by dressing tidily or by improving their physique. Understandings of disclosure in HIV programs and explanatory tropes such as “self-stigma” reflects a self located within what Carla Jones has called, “an imagined social landscape of potential missteps, contexts in which the self was a possible barrier to smooth interpersonal relations” (2010, 274; see also Simon 2012). Outreach workers identified “self-stigma” primarily not as an issue that lay within an individual or was related to the internalization of social and cultural norms, but emphasized that it stemmed from concern about the unruliness of the body as an external locus of self-actualization.

At the other end of the spectrum of this paradigm of visibility were those who were “closed” (tutup), given their normative appearances and that presence in locations that made them hard to see. Outreach workers trained themselves and one another to become literate in spotting the visual signifiers and performative markers that prospective MSM displayed in public. As one outreach worker explained, “So, each time we mapped out locations, we just look at the people, like at the mall. We just look at the characteristics: how old they are, what they look like, so we already know from their appearances [whether they are MSM].” No matter how careful the performance, an expert, and especially someone from that community, could still always discern a status as MSM or HIV positive through their appearances. Malls, the locations where the vast proportion of the city’s middle-class residents and those who aspire to it gather to spend their leisure time, were a site where outreach workers developed a specific set of skills to watch for and identify people who looked like MSM based on physical traits. At one outreach event I attended in a mall, the Bergembira staff and I were seated behind a table with a banner advertising a safe sex campaign behind them. One outreach worker leapt up from his chair and rushed towards two handsome, well-dressed men who emerged from a store holding the latest version of an expensive cell phone. After a brief exchange, where they laughed off his request that they sit and chat with him, he returned and explained, “That’s typical for MSM, Ben: they don’t have enough money for their rent, but they’ll buy brand name phones and clothes. You can see MSM because of their sophisticated (canggih) appearances.” This outreach worker here observed the behavioral profile of MSM in a desire for consumer goods, recognizing their sexuality from their appearances in the form of an aspirational middle-class status.
In each of these cases, outreach workers engaged with an understanding of visibility that was framed in terms of forms of selfhood premised as either “open” or “closed.” These were not stable states but depended on the social context. Partially mapping onto the political economy of HIV aid, in which funding was tied to locating new clients, outreach workers expended considerable effort explaining to me the nested relationship between “opening” a person’s status as an MSM and as an HIV positive person. Given the high stakes of concealing this doubled “status” for the individual concerned, outreach workers cultivated various methods to read the body for signs. The centrality of visibility to interpreting the meanings of the HIV positive individual reflects a condition that Adia Benton has called, “the multiple registers in which the gaze and spectatorship come to articulate specific kinds of social relations among HIV-positive people” (2015, 93). In her account of HIV positive support groups in Sierra Leone, Benton describes how members of these groups navigated their visibility to others, the meanings of which were informed by “a set of social practices and orientations, mediated judging relationships among the HIV-positive individuals” according to “a hierarchy of positivity” judged according to compliance “with institutional and interpersonal demands to live positively” (2015, 90). Such forms of visibility differ from one context to another, depending on the audience (see also Black 2015). Similarly, in Indonesia, both HIV positive people and MSM were required to manage their visibility within a shared cultural field of visuality, albeit one that was influenced by forms of discipline centered on the body that rested on knowing when to be “open” and when to be “closed.”

Across diverse contexts globally, biomedical and psychological models for responding to HIV-positive individuals demand a subjective transformation at the level of the self in which they become responsible for their own treatment. An emphasis on disclosure, found in social contexts which range from support groups to doctors’ consultation rooms, inculcates in HIV positive persons an ethical responsibility to care for themselves and others (Nguyen 2010). Living positively as an HIV positive person among MSM in Jakarta nevertheless demanded being visible to audiences in the right way, extending to appropriate clothing and comportment, the timing of disclosure, and appearing healthy to others. The visibility of the biosocial body was not only related to HIV but intersected with both the aspirational class status reflected in the “sophisticated” and “ngondhek” appearances of clients. As a result, assumptions about disclosure as a default position in global HIV programs were transformed as they encountered Indonesian understandings of personhood and the self, which were shaped by efforts to transform one’s comportment and appearance as it was visible to others.

**Conclusion**

Even as Raja was a problematic figure in an age of widespread access to pharmaceutical treatment, his was a common enough story in the landscape of Jakarta’s HIV programs. His body rendered him problematically visible because he had failed to disclose his HIV positive status “in time.” During our first visit to the clinic with which I opened this article, his visible ill health was reflected in a low CD4 count, in addition to a tuberculosis diagnosis. Nevertheless, as we sat having lunch following his appointment, Raja continued to describe about the possibility he could live a “healthy life” (hidup sehat) in the years to come. He stressed that to be able to look healthy, he needed to make a decent living so he could present himself well. If he could just find a decent job and live alone, and eat at regular times, he could obey the doctor’s instructions to take his medication after breakfast and dinner. In doing so, he would gain weight and get a job, which would allow him to be seen as a
respectable person in the eyes of others. As he moved to take the first of a lifetime of medication in front of me, his body shook violently, as though it was resisting taking it despite his inner will to do so. With much effort, he swallowed two small tablets, his body trembling for minutes afterwards. It was these everyday practices, twice daily taking medication, dressing neatly every day, avoiding inadvertent slips into a feminine gender presentation, which transformed disclosure into a demand to control his body in contexts where this seemed an arduous task. Refigured as embodied liability, disclosure of and even coming to know one’s HIV positive status was a double-edged proposition; it was necessary to receive treatment but to do so was to risk the possibility of exposing oneself as a form of moral contagion.

Outreach workers’ efforts to get clients like Raja to enroll and stay in treatment seemed preoccupied with the management of clients’ visibility at the level of the self. This may seem a curious concern, one that extends beyond the rationalized frameworks of biomedicine or psychology. But their attention to the problem of knowing when to be open and when to be closed reflected its importance to the many clients from lower-class communities or were gender nonconforming in some way. For outreach workers, many of whom came from these very communities, knowledge about HIV treatment was felt as an acute sense of responsibility. They translated this responsibility into efforts to discipline the appearances of their clients so that they disclosed their status in appropriate settings while remaining invisible in others. For both outreach workers and their clients, then, the self was imagined as akin to a liability that had to be managed as a shared responsibility.

A growing emphasis on testing and treatment as demonstrable end goals in HIV outreach programs has reconfigured the role of organizations like Bergembira. Rather than concerned with translating social knowledge into messages about safer sex that make sense to constituents, outreach workers see their task as communicating global biomedical and epidemiological expertise. They are expected to reduce the number of clients who are “lost to follow up,” channeling people into testing and treatment, and ensure that they remain visible within pharmaceutical and diagnostic systems. Framed as a form of bureaucratized work measured by improvements in the number of people tested and treated over time, outreach work can be understood as part of efforts to paper over the messy social reality that living with HIV entails, and to conceal the ongoing presence of the many people who cannot access treatment in a timely way. Outreach workers continue to struggle to manage the visibility of the HIV positive person as someone who does in fact continue to suffer from illness and poverty.

Without increased funding for Indonesia’s beleaguered healthcare system, and framed as an external appendage to global HIV responses which prioritize pharmaceutical solutions, the option that made the most sense to outreach workers was to manage the visibility of the HIV positive person as they navigated clinical settings. In their efforts to discipline the visibility of the HIV positive person, outreach workers reveal both inequalities in access but also the limitations of models in which the burden of “ending AIDS” ends up resting on the individual. Raja’s experiences reveal a dilemma of HIV programs and their emphasis on disclosure at the level of the self: where treatment represents a clear pathway to full biological citizenship, to be poor or unwell is a form of failure. In learning to manage signs of who he had become and the virus that he carried, Raja came to occupy a body that

This article is protected by copyright. All rights reserved.
was caught between disclosure as a form of visibility necessarily for treatment and the demand to remain invisible, a predicament that was hard to escape.

BENJAMIN HEGARTY is McKenzie Postdoctoral Fellow in the School of Social and Political Sciences at the University of Melbourne. He is also a Research Fellow at the AIDS Research Center for Health Policy and Social Innovation at Atma Jaya Catholic University, Indonesia.

Acknowledgements

In addition to the study participants at partner organizations in Jakarta, I am grateful to both Sandeep Nanwani and Ignatius Praptorahjarjo for their keen insights and continuing collaboration. Earlier versions of the article have benefited from stimulating questions and criticism from audiences at several institutions. I am grateful to audience members at the Utrecht University “Doing Gender” lecture series in 2019 and to Christine Quinan for their invitation to speak; fellow panelists and audience members at the EuroSEAS conference panel “Queer In(Visibility)” (2019) and Sylvia Tidey for bringing such an exciting group of scholars together in Berlin. My gratitude to colleagues in Anthropology and Development Studies for their comments in the “Brown Bag” writing group, which helped to sharpen my perspective on the central ethnographic themes. Greg Downey provided extensive editorial advice. Fieldwork was possible thanks to grants from the Australian National University Indonesia Project Research Grants, administered by the SMERU Research Institute in Indonesia, and The Melbourne Law School, through its Indonesian Democracy Hallmark Research Initiative (IDeHaRI). Ethics approval for the earlier components of the study (2017-2018) was granted by the Australian National University (2014/465), and for a subsequent visit (2019) from University of Melbourne (1852983.1) and Atma Jaya University (0671/III/LPPM-PM.10.05/06/2019) Human Research Ethics Committees.

References


This article is protected by copyright. All rights reserved.


This article is protected by copyright. All rights reserved.


This article is protected by copyright. All rights reserved.


Notes

1 MSM is a widely used category in the everyday language of HIV activism and work in Indonesia, and has moved well beyond its use as an international epidemiological category created to alleviate both the stigma and political frisson linked to the Western categories “gay” and “homosexual” (Boellstorff 2011). MSM has since been subject to various forms of critical engagement from medical anthropologists and critical public health scholars, including that an acritical use of the term can reify “local” cultural categories in ways that limit more dynamic understandings of sexuality (Boyce 2007). This article joins recent attention by medical anthropologists to attend to the work that the category MSM performs as it classifies populations and individuals according to broader cultural logic of the political economy of global health (see for example Boyce and Cataldo 2019; Biruk 2019).

2 Quantitative studies have varied widely in estimates, no doubt due to the difficulty of estimating population size and logistics of conducting biological and behavioral surveys in such a large archipelagic nation. Yet one recent cohort study undertaken in four Indonesian cities found that, out of the total number of MSM who tested positive to for HIV,
approximately 20% were “lost to follow up,” meaning that they did not make any contact with the clinic to obtain medical care in the six months following their initial test results (Januraga et al. 2018). In this study, those most likely to commence treatment, perhaps unsurprisingly, had a positive test result in a location that offered treatment.

3 The “cascade of care” is a dominant policy paradigm in HIV programs, and is generally shaped by corresponding indicators such as 90/90/90, which reflect 90% of at risk populations having taken a test, 90% of people who test positive enrol in treatment, and 90% of those who enrol in treatment have a suppressed viral load. The cascade of care means many things as it has been taken up as a concept in global HIV programs, both a narrative format for living with HIV at the individual level and a means to undertake monitoring and evaluation at the population level (see Molldrem 2019).
Minerva Access is the Institutional Repository of The University of Melbourne

Author/s:
Hegarty, B

Title:
The Biosocial Body: HIV Visibility in an Age of Pharmaceutical Treatment in Indonesia

Date:
2022

Citation:

Persistent Link:
http://hdl.handle.net/11343/297721