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Strategies of silence in an age of transparency: Navigating HIV and visibility in Aceh, Indonesia

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ABSTRACT

This article explores how strategies of silence intersect with politics and predicaments of visibility. Contributing to historical and anthropological scholarship that asks how histories of violence shape individuals' subjective navigation of silence, it suggests that the everyday work of silence needs to be understood within historical configurations of articulation in which (in)visibility takes an important place. Situating narratives of people living with HIV in Aceh, Indonesia, within recent local and national histories of violence, it shows how their strategies of silence and (in)visibility unfold within a bureaucratic urge of transparency and a social climate of anxiety about appearances. Extending anthropological insights on silence as an often powerful presence in social life by highlighting the dynamic of the (un)spoken and (in)visible, its central argument is that silence, speech and visibility can be fruitfully analyzed on a continuum of articulation and non-articulation.

KEYWORDS

Silence; narrative; HIV/AIDS; Indonesia; health care

Ita's beauty salon looked quiet, with its front doors shut to keep out Banda Aceh's sizzling heat and dust, no other cars except ours and no customers in sight. I watched Rahma, an HIV support group staff member, enter the salon that was housed in one of the city's many 'shophouses', with a shop downstairs and living quarters upstairs. She returned a few minutes later, phone at her ear. It was the 31st of May, 2014, almost nine months since I started my ethnographic fieldwork with the only HIV support group in Aceh, Indonesia. It had been a long day in the hospital, where support group staff had accompanied a number of HIV-positive members on their medical appointments, assisting with paperwork, prescriptions and clarification.

At the end of the day, we finally had the chance to try and find out what happened to Ita, one of the *waria* (transgender woman) members of the group. Diagnosed with HIV more than a year earlier, Ita had become an active force in the support group, contributing to focused group discussions and karaoke evenings, and regularly joining the four staff members in the hospital, making everyone laugh with her witty jokes during the long hours of waiting in the polyclinics, the pharmacy, and the canteen. At the same

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time, she had herself resisted starting anti-retroviral medication, saying she was afraid she would not be able to stick to the time schedule of taking the pills. Support staff told me that she was also scared that she could not hide the medication in the beauty salon where she lived and worked. Ita was terrified that her family, and especially her friends in the *waria* community would find out about her HIV status. She had witnessed more than once that an HIV-positive person was ostracized upon (involuntary) disclosure and countered the suspicious questions of her *waria* friends with outright denial and sharp reproaches.

In early May, she suddenly fell seriously ill with high fever and was admitted to the emergency ward of the public hospital. Her mother and brothers came from their village, a six-hour drive from the city, to take care of her on the ward. On my visits during those weeks, I saw Ita becoming increasingly anxious, first saying that the people in her village had heard about her HIV status, later whispering that her *waria* friends all knew and would be coming to visit her soon. When trying to visit her on that morning of the 31st, we found she had disappeared from the hospital. Medical staff told us she had left, but could not provide us with further information on the reason of her apparent self-dismissal. They also did not have a family phone number, but her *waria* friends in the salon did. On the doorstep of the place where she had long worked and lived, her brother told Rahma on the phone that she had insisted on going home and then passed away soon after their arrival in the village. She had not been able to bear the thought of her *waria* friends seeing her there, like that, the support group staff concluded.

Ita was one of the thirty-plus people living with HIV whom I met with during one year of ethnographic research on HIV care in Aceh.[1] Her narrative, which I will recount in more detail below, was one of the many in which the navigation of silence and secrecy, visibility and invisibility were central concerns, and indeed matters of life and death. Although I had previously lived in the area to study the aftermath of the devastating and highly mediatized Indian Ocean tsunami (Samuels 2019a), my research on HIV brought me into much more concealed parts of Aceh's everyday life. Here, as elsewhere, HIV was a highly stigmatized affliction and for people living with the virus avoiding public disclosure meant preventing social death. At the same time, as state health care programmes demanded a certain amount of visibility in order to reach health targets in a transparent way, to access health care, people living with HIV had to balance potentially dangerous exposure against the health risks of not starting with, or not adhering to, regimes of antiretroviral medication. For people leading non-heteronormative lives, like Ita, such exposure presented a double danger. Under Islamic law, implemented in Aceh since 2001, LGBTQ-people have come under ever higher surveillance and *waria* spaces have regularly been raided by the Shari'a police, who arrested *waria* to 're-educate' them about Islam. In this setting, presenting oneself to any state agency – including those concerned with health – could be risky.

A careful navigation of secrecy is far from unique to HIV-positive people in Aceh (see, e.g. Black 2015; Moyer 2012). As Moyer and Hardon (2014) have argued, in an age of widely available antiretroviral therapy, HIV remains exceptional: Whereas voluntary public disclosure of HIV-infection has generally been encouraged to make HIV a disease 'like any other', the social stigma hardly decreases, making silence the preferred and most livable strategy for many people living with HIV. Often, HIV-positive persons' strategies of silence are a form of care, both for others and for themselves (Hardon and Posel 2012). Yet although experiences of HIV and silence show many similarities across time and space, they are also shaped by particular social, cultural, and political configurations, as well as individual biographies. In Aceh, I suggest in this article, anxieties about HIV occur within a history of violence and disaster, and in relation to an obsession with transparency and, at the same time, a concern about visibility that intensified after the step-down of the Indonesian president Suharto in 1998.

In exploring individuals' work of silence in this particular socio-historical context, I have two main objectives. First, I ask how large-scale societal and political configurations of silence and articulation, transparency and invisibility, come to shape possibilities of care for (and by) people living with HIV. By addressing this question in the particular context of Aceh, I add to an emerging field of historical and anthropological studies that ask how histories of violence intersect with individual pasts in the subjective navigation of silence for those who have most at stake (see, e.g. Good et al. 2008; Kidron 2009; Pipyrou, forthcoming).

Secondly, I suggest that attending to this subjective work of silence demands that we inquire into the relations between silence and (in)visibility (see also Chatzipanagiotidou and Murphy, this issue; Dragojlovic, this issue). If this relation is generally striking in post-Suharto Indonesia, where the anxiety about appearances has become a prominent part of society and the source of sometimes deadly rumours (see, e.g. Bubandt 2008; Herriman 2015; Kroeger 2003), it is especially crucial for people living with HIV. As medical anthropologists have shown, to keep the secret of HIV diagnosis, people often put a lot of body work into appearing healthy, using particular strategies of visibility and silence in tandem (see, e.g. Rhine 2014). Health care bureaucracies, at the same time, attempt to make people legible, visible, less by their healthy appearance than by their diagnosed disease and other biomedical indicators. To those living with HIV in Aceh, the importance of managing (in)visibility as part of secrecy and care, and in relation to speech and silence, opens up the question of how to think of silence alongside visibility. Attending to strategies and limits of silence and visibility in the everyday work of secrecy and care, I suggest that silence, speech and (in)visibility may be fruitfully analyzed on a continuum of articulation and non-articulation along which perhaps it is silence that, because of its opacity, takes the most multifaceted and ambiguous forms (see also Dragojlovic 2020; Weller 2017).

In what follows, I will first situate this line of thought within anthropological work on silence and narrative and sketch the historical context in which appearances of and silences about HIV come to matter in Aceh. I then elaborate on Ita's story and the predicaments that *waria* face because of their visibility, vulnerability to HIV, and limited social support. However, it is also those with heteronormative sexualities that struggle with visibility and silence. Following on the story of Ita's last weeks, I draw on the narrative of a young mother, Farida, to illuminate her careful navigation of speech, silence and (in)visibility. I draw attention to her efforts of balancing the risks and needs of visibility through speech and silence, as well as the subjunctivizing elements in her narrative of her past and future that indicate parts of her world that she can articulate to only a few people, if anyone at all. In the conclusion, I return to the ways in which the navigation of silence and (in)visibility in Aceh reveals socio-historical formations of anxiety in Aceh and Indonesia. Finally, I suggest that attention to the politics and predicaments of visibility in relation to the unspoken and unspeakable may help us better understand the meaning and power of social silences in everyday life.

Narratives and silences

Silences shape the stories we tell, enact and imagine. For each story told, many others remain untold, and, as Robert Weller argues in this issue, it is the untold stories that make the rhythm of what is spoken. These silences are the ground of stories, between the narrative heartbeats, as Weller's apt metaphor brings out. They may also be stitched *within* narratives – in moments of hesitation and doubt, in ambiguity and rumours, carefully circumvented taboos, and unfinished sentences that indicate the presence of the unspoken, unspeakable, even unthinkable. They become ephemerally illuminated in what Merav Shohet (2017) has called 'sideshadowing narratives', the offhand remarks and whispered stories that indicate alternative readings of social life. Sometimes, silence undergirds an entire story and can be sensed in what Veena Das (2007) has called a narrative's 'frozen slide quality'.

Historians and anthropologists, including the contributors to this special issue, have shown how individuals' engagement with possibilities of silence and speech emerge in particular social, cultural and political situations. For example, in her work on the painful memories of people who, as children in 1950s Calabria, had been displaced and involuntarily separated from their parents after severe floods, presumably as a form of humanitarian 'care', Stavroula Pipyrou (forthcoming) shows how the structural silence of history textbooks and national narratives intersects with the embodied silence of the now elderly displaced children, who have long learned to occupy and 'live within the space of silence'. Similarly, for Indonesia, recent scholarship on the historical national silence about the 1965–1966 mass murders against alleged communists and the ways in which survivors and perpetrators have lived with silence for decades in order to maintain communities, shows how silence shapes political subjectivity (Leksana 2019).

A vital contribution of the anthropological scholarship on silence, then, is its attention to the entanglement of the politics of silencing and the silence work that individuals do to create and maintain their social worlds. Here, studying silence means attunement to political and psychological forces (Good 2012) and to a continuum between what Tine Gammeltoft (2016, 429) distinguishes as 'deliberate' and 'subconscious' silence, the consciously unspoken versus the silences of which people 'are cognizant and yet not', the 'not-fully-conscious'. As Merav Shohet (2018a) points out, becoming aware of such silences may require more, rather than less, attention to narratives. Such narratives are not only discursive, but also enacted, dreamed, danced, painted, or imagined (Jackson 2002; Mattingly 1998). As Carol Kidron (2009) shows in her work on the silent presence of Holocaust memories, the use or presence of objects may keep memories present even in the absence of spoken words. Such objects, like artworks, as well as ambiguous, 'sideshadowing', or 'frozen slide quality' narratives may point, moreover, to the limits of what can be articulated. They show how experiences at the limits of the speakable or thinkable may themselves vary in their potentiality of articulation (see Throop 2010).

Attending to silence, then, compels us to study how spoken narratives relate to other forms of (non-discursive, particularly visual) articulation, to the limits of speakability, and those experiences and histories that cannot be articulated at all. Reading the anxieties about appearances and apparitions that have taken hold of Indonesia, and particularly Aceh, in the past two decades from the perspective of people living with HIV brings the political and intimate relation of silence and (in)visibility into view.

HIV, transparency and invisibility in Indonesia

The first case of HIV in Indonesia was diagnosed in 1987. The epidemic started relatively slowly in the 1990s, but infection rates increased rapidly in the new millennium. In 2004, the Indonesian government started to implement a national programme for AIDS prevention and treatment. Despite antiretroviral therapy being available free of charge, adherence to medication remains worrisomely low (UNAIDS-Lancet Commission 2015, 175).[2] Recently, the Global Fund to fight AIDS, Tuberculosis, and Malaria has decreased its contribution to the national programme, meaning that a larger number of care and prevention activities have to be funded from the universal health coverage system implemented in 2014. Although the endorsement of this new health financing system is promising, it remains to be seen whether it can solve the huge problems with access to and quality of health care in the archipelago (see, e.g. Nanwani and Siagian 2017; Pisani, Kok, and Nugroho 2017).

Indonesia's northwesternmost province, Aceh, is widely known for the devastating Indian Ocean tsunami that caused more than 170.000 deaths in 2004, the violent separatist conflict that ended in 2005 after three decades of violence, and the implementation of Islamic law since 2001. HIV is rarely linked to Aceh's public image, which is no surprise given its relatively low prevalence. The first case of HIV was diagnosed in 2004 and ten years later about 300 people had been diagnosed, mostly with AIDS, in a population of 4.5 million.[3] Although testing could be done in most district hospitals, at the time of my research in 2014, antiretroviral medication was available only in the provincial public hospital in Banda Aceh, the provincial capital.[4] As the maximum dosage of medication provided was for one month and its distribution was accompanied by a physical check-up done only in the provincial hospital, patients had to travel to Banda Aceh monthly. Moreover, since most district hospitals claimed not to be 'ready' for treating HIV patients, patients often had to also travel to Aceh's capital for afflictions ranging from toothache to diarrhea, and from skin lesions to tuberculosis. For many, this meant that a visit to the hospital amounted to a trip spanning multiple days, and a significant expenditure on transportation, food and lodging. Sometimes the refusal to treat HIV-patients locally had immediate deadly results, such as when district hospital staff claimed not to be ready for an emergency cesarean section on a young HIV-positive woman and sent her on an eight-hour car-ride to the provincial capital. Although the woman survived the ordeal, the baby did not. Often, people decided to wait until symptoms got worse instead of draining scarce resources for a visit to the provincial hospital. Less visible still were the cases in which people altogether refrained from returning for follow-up care.

Similar to what Dlamini-Simelane and Moyer (2017) have recently argued in the case of Swaziland, it is not necessarily the availability of medication, but a complex array of social factors such as transportation, gender inequality, and fear of disclosure that accounts for the many patients who become bureaucratically categorized as 'lost-to-follow-up'. In Indonesia, as elsewhere, maintaining silence and secrecy to prevent disclosure and ensuing social stigma and discrimination are central components of a life with HIV (Boellstorff 2009; Butt 2011; Hidayana and Tenni 2015). In Aceh, many people think of the presence of HIV as especially embarrassing with respect to the province's implementation of Shari'a law and its generally pious Islamic image. Whereas global standards of HIV treatment and prevention include encouraging patients to publicly disclose their status in order to increase social acceptance, in Aceh counsellors regularly advised to not disclose one's positive HIV status or only entrust the secret to selected relatives. Involuntary disclosure could have detrimental effects, ranging from one's children being denied access to school and the foreclosure of livelihood possibilities, to forced displacement from the village or abandonment by family and friends.

For people who do not regularly travel long distances – especially women – a sudden trip to Banda Aceh will certainly raise questions from neighbours (Samuels 2020). The required monthly check-up in the hospital is even more difficult to conceal from one's social environment. Moreover, to access medical care in the provincial hospital, patients need a referral letter (*rujukan*) from their local clinic, which is often staffed by acquaintances who might not keep the diagnosis confidential. In the clinic, 'HIV' is sometimes stamped in large font onto their documents, increasing the risk of public disclosure. All of this, added to the fear of encountering an acquaintance in the provincial hospital, deters many from seeking medical care until they are very ill.

For health care staff and government officials, categorizing patients as either adhering to treatment or lost-to-follow-up matters. I frequently heard them worry about not reaching their top-down formulated targets for outreach activities and numbers of patients taking ARV medication. The continuous 'disappearance' of patients from the official health care system caused a chronic failure for Acehnese officials to reach the treatment coverage targets. From a bureaucratic perspective, it was this bureaucratic data gap – rather than the deficiencies of care that the missing data represented – that became the primary governmental concern. If making reporting data an end in and of itself is a general feat of developmental governance (see, e.g. Li 2007; Scherz 2014), in Indonesia it also intersects with a need for transparency that has become a national obsession since the step-down of the authoritarian president Suharto in 1998. At the time, people frantically wanted to see what the state was doing and simultaneously wanted to be 'seen', to be recognized (Strassler 2004). The focus on transparency dovetailed with the international discourse of 'good governance', even though anxious attempts to maintain a transparent bureaucracy are paradoxically leading to new forms of corruption, as people may need to spend some extra under-the-table money to make sure documents *look* good (Tidey 2013). Generally, then, the urge to see did not bring more certainty or a larger sense of security. Indeed, state projects of legibility, visibility, and spectacle had since colonial times often taken violent forms (see, e.g. Siegel 1998). As Mary Steedly (2013, 262) has pointed out, after the decentralization of state power post-1998, such violence became decentralized too, and thereby 'the compulsion to see and be seen [was] continually brought to crisis by the terror of seeing and being seen'.[5]

During these same early years of the new millennium the anxiety about the unseen was magnified in Aceh, where a conflict between the Indonesian army and separatist fighters (the Free Aceh Movement, GAM) that had been going on for decades became even more violent. As Reza Idria (2019) writes, the Acehnese had long lived with unseen forces, including *jinns* and spirits of the dead. But, Idria elaborates, during those years of violence, the invisible became increasingly uncanny. Daily killings, always ascribed to 'unknown people', instilled terror, and officials likened the GAM combatants to 'communists', the haunting ghosts from the massacres in 1965-66 (Idria 2019; see also Good 2015). After the conflict ended with a peace agreement in 2005, these combatants who had been hidden in the mountains suddenly appeared, uncannily, in public (Good 2015). But first, the 2004 tsunami caused another massive encounter with absence and ghostly presence, with uncountable dead bodies buried in mass graves, unidentified (Idria 2019). Idria argues that the many NGO workers that flocked to Aceh in the aftermath of the disaster were in a way also experienced as ghosts; unreachable, ungraspable, uncertain. The Acehnese tsunami and conflict survivors were simultaneously enthusiastic and worried about the sudden influx of outsiders and the values they brought with them (Idria 2019; Samuels 2019a).

HIV diagnoses started to slowly appear in Aceh during these same post-tsunami years and many Acehnese came to see the virus as one of the unseen dangers that had come along with the outsiders entering the province, an invisible force that people wanted to see but at the same time were terrified of seeing (see Samuels 2016). HIV in Aceh, then, arrived on top of ghosts of communism, separatist militants, tsunami dead and unreachable NGO workers, in a time during which, as Byron Good (2019, 412) has put it, 'a society is shaken by the appearance of ghosts'. The felt urgency to properly see, identify and count HIV in Aceh became apparent not only in health bureaucracy targets but also in the regular bold headlines in provincial newspapers, ominously proclaiming the numbers of infections in particular districts. Such public messages did little to increase awareness about prevention and care. Instead, people responded with anxiety about the invisible presence of HIV, which had the possibility to appear there where one could not have seen it. People living with HIV, such as Ita, were faced with carrying not only a deadly virus but also an invisible and morally fraught force perceived to be threatening Acehnese society. As a *waria* in a province that had become increasingly dismissive of non-heteronormative sexuality in the past years, Ita faced a potential double stigma. Yet, while she could battle the stigma of visible non-heteronormative sexuality together with her *waria* friends, the stigma of the virus that she kept secret through silence and physical beauty loomed within her everyday social world.

Ita: silence, secrecy and the violence of being seen

Two months before Ita died, we were standing together in the morgue of Banda Aceh's public hospital, watching the dead body of Lizzy. Lizzy was a *waria* who had been abandoned by her family and, after various conflicts, had equally been unwelcome in Banda Aceh's transgender community.[6] Presently, her brother anxiously approached as support group staff invited him to close her eyes, emphasizing that he would not risk infection by doing so. As I watched, I felt Ita gripping my shoulder tightly.

Officially, Ita was there as an HIV counsellor. The previous year, she had attended an HIV counsellor training in Java – an amazing experience, she told me; it was her first time outside of the province and she now had friends all over the archipelago with whom she kept in touch through social media. The counsellor status protected her as she countered her friends' questions about her engagement with the support group by arguing she was a counsellor, but not HIV-positive herself. Ita had become an expert in fending off difficult questions. She told me, for example, that when her boss had inquired whether it was true that she was HIV-positive, she had replied, 'Of course not, that is just gossip of uncivilized *banci* [derogative term for *waria*]' (*gosip banci-banci yang tidak berkelas*). When people asked why she was so skinny, she replied she had Dengue fever. And when another *waria* had asked her recently whether she had HIV, she had responded, 'You should watch your mouth. Who told you this? It means that person herself has HIV. Don't go around carelessly accusing people, you could be sued!' But the suspicions weighed on her and she sensed that more and more people started to ask questions and spread rumours.

Despite her counsellor status, Ita kept avoiding antiretroviral medication for a long time.[7] She was just *bandel* (naughty, unruly), she told me. For health workers she was a 'lost-to-follow-up' case in plain sight: they could reach her, talk to her, but not convince her to start therapy. Lizzy's death, however, was a turning point. Within weeks, Ita started the prescribed regimen of cotrimoxazole, mandatory before starting ARVs. She was anxious, had fevers and a terribly dry mouth. She told me she hoped this would pass and that she aspired to open her own beauty salon in the future. But she also said she had called her mother, and told her, 'Ma, perhaps I am leaving earlier than you'. Her mother had replied that she should watch her words, saying 'Don't think your life is in *your* hands'. As she thereby reminded Ita that only God decides on the end of life, she responded to Ita's reference to dying with the open-endedness of the unknowability of fate. Ita's reference to dying young, however, presented a 'sideshadowing narrative' (Shohet 2017, 2018a) of her future, one that Ita reiterated when she told me about the phone call, alongside her aspiration of owning a beauty salon. Briefly pondering a subjunctive, 'what-if', scenario, the possibility of death, as a shadow alongside a figure (Shohet 2018a), displayed and invoked ambiguity and open-endedness in her narrative navigation of the world (see Samuels 2019b).[8]

Ita did not get to start taking ARVs. Mid-May, in the crowded emergency ward, with her mother present, Ita whispered that we should call her by her birth name, Andi. And when the others went off to talk to the attending physician, she told me that she thought that now everyone in her home village knew about her illness. Her mother knew, but did not understand; her brothers were certainly suspicious. As the fever continued, she became increasingly nervous and anxious. When, upon hearing the news of her death a support group staff member said that her request to go home was the result of her anxiety about her *waria* friends coming to see her, I sadly thought of the morning in the morgue, and how Ita ultimately had prevented her community from seeing her in the way she had seen Lizzy.

If Ita's navigation of silence can be understood in relation to general social stigma and the post-tsunami association of HIV with a dangerous outside force, it is compounded by the rising marginalization of queer people in Indonesia, and particularly in Aceh. In the years after my fieldwork, state and vigilante violence against LGBTQ-people in Indonesia increased dramatically (see Human Rights Watch 2018). As the most visible targets of such violence, many *waria* flew from Aceh to temporarily settle in bigger cities. But also already in 2014, *waria* in Aceh were highly insecure, not in the last place because an increasingly strict implementation of Islamic law (Thajib 2018). Historically, *waria* have had an ambivalent relation to visibility, as their striving for bodily transformation to be visible on 'the national stage' has, Benjamin Hegarty (2018, 355) argues, both animated and undermined 'the fragile promise of national belonging in Indonesia'. The (national, mass-mediated) visibility of other *waria* that emerged during the New Order regime (1966-1998) allowed *waria* to recognize themselves as *waria* and to gain public recognition of this identity – and yet it was this very visibility that could result in violent reactions from the same public (Hegarty 2018).[9]

The risks of being seen as *waria* become especially obvious in HIV care. In Aceh, the women's wing of a large national Islamic organization was tasked with HIV outreach and awareness raising among 'key populations' – a task assigned to them through a national level distribution of AIDS care tasks to various organizations. In several interviews, the female outreach workers conveyed to me their frustration with the impossibility of reaching their targets among *waria*. Ita, meanwhile, told me how once, during such an outreach session with the *waria* community, all *waria* had been required to give their names and addresses for proper bureaucratic accounting. The next day, one of the *waria* had been arrested by the police, in her own house. Since that day the *waria* did not want to have anything to do with outreach workers. The *waria* community was the only 'safe space', the only space where one could live as *waria*, but not if one was known to be HIV-positive.[10] State, and state-like, attempts to make the already visible *waria* in Aceh more legible could result in violence, for example in programmes for *waria* 're-education', which constituted human rights violations that were presented as state care. In such a space, state attempts to make HIV visible among a group that was already vulnerably visible in a gendered way, effectively silenced possibilities of speaking out on HIV infection, prevention, testing, and treatment.

Ita's precarious work of silence on HIV and showing visible health and beauty that allowed her to be part of the *waria* safe spaces became increasingly untenable. As her health deteriorated and rumours mounted, she ran up against the existential terror of 'being seen' as a person living with HIV – a *waria* living with HIV, risking a double exclusion from the nation and the beauty salon. She was, in Hayder Al-Mohammad's (2015) terms, 'falling out of the world', losing her precarious relations with the world; relations that had required continuous effort to begin with. HIV disclosure risked her being ostracized from the only community where she could be recognized and valued as *waria*. Ita once told me that she did not have much success as a counsellor. None of the friends she invited to get tested accepted the invitation. They were *malu* (embarrassed, ashamed), she said. Being known as living with HIV within the *waria* community and beyond would be unlivable, making the possibility unspeakable.

Embarrassment about a (possible) HIV infection, I found, was certainly not limited to those most visibly exposed to stigma. It also affected those leading heteronormative lives, especially wives and widows, though perhaps in a different way. In the next section, I recount the story of Farida, a young HIV-positive widow with two daughters, one of whom was infected as well. Like Ita, she struggled with silence and misdirected health care programmes that aimed to reach targets and transparency without protection of those who became visible as a consequence. In contrast to Ita, however, she did so by ambiguously highlighting her sexuality.

Farida: navigating silence and the spectre of shame

On the very first day I started participant observation with the support group, I met Farida. She had come from her village, a six-hour drive from Banda Aceh, together with her mother and two daughters, aged three and five years old. Farida and her youngest daughter were HIV-positive and needed to have their blood drawn. We did not get to talk much, as all our attention went to the young girl who was terrified of the needles. However, we met more frequently over the following months, every time Farida came in for her monthly check-up and medication. Dressed according to current Islamic fashion and always with carefully applied make-up, the young mother regularly shared with me and support group staff and members that she was looking for a new husband. Her first husband had died a few months earlier, in June 2013, and even though others advised her to grieve and wait, she felt a strong urgency to get married again quickly to someone who was also HIV-positive. In December 2013, she told me she would never dare to disclose her status to someone without HIV and wanted a partner who would fully understand the predicament of the illness. She needed the support group for this mission, because this was the only place where people living with HIV could find each other. She had a number of other criteria, she told me, namely that he should be relatively handsome, have a good job, and no children. In matrilocal Aceh husbands move in with their wife's family upon marriage and this was the assumption behind Farida's final criterion: His family should live far away from hers, so that if Farida and her husband would go to Banda Aceh for medication they could satisfy her neighbours' questions by telling them they were visiting her in-laws. A husband would give her freedom to travel, while now she was dependent on the permission of her parents. But, she stressed, it would have to be someone she really liked.

It was in June 2014, in the confidential space of the support group office and with my tape recorder running, that she told me a longer story. She seemed nervous about the interview at first, not entirely sure how to tell her story and moreover continuously interrupted by her youngest daughter who was playing with her cell phone. Yet, after half an hour, when her daughter had fallen asleep and the relatively informal character of our conversation had become more apparent, her stories became more and more extensive and she kept returning to details that she had mentioned earlier, giving them further weight by repetition and elaboration. Farida started by telling how she had met her husband in the early 2000s, when they were both attending university in Banda Aceh. They married and upon graduation returned to her district where they both acquired sought-after government positions. She became a teacher, they had two daughters and led a comfortable life. Then suddenly, in 2012, her husband fell ill. The doctor first diagnosed pneumonia. After the fifth visit to the district hospital, he noticed low CD4 levels in the blood test results and recommended an HIV test. Farida resisted the idea, because she thought that it would not make sense to do such a test if there was no cure to this illness. They only did the test when after several months his symptoms worsened. After the test results of her husband came back positive, Farida and the children got tested as well. Only the eldest daughter was not infected.

In the past year, Farida continued, she had come to 'accept' (*menerima*) the affliction, but it had not been like that at first. When she first heard she had HIV, she just did not believe it, thinking that 'this was an embarrassing disease, a disease that people bring upon themselves'. Against the doctor's and support group's advice, she refused to take medication, and, as she put it, her husband followed her decision. From the health care system's perspective, they were then 'lost-to-follow-up', only to return six months later when he was very ill. He stayed in the hospital in Banda Aceh for one month, and it was there that Farida's perspective on antiretroviral medication changed. Influenced by the doctors and support group, she started to insist on taking the medication and even tried to convince his family that he indeed was suffering from AIDS. Yet his parents continued arguing what they had been saying all along: He was a victim of black magic (*guna-guna*) and should be treated by local healers (*dukun*).[11] Crying, Farida related how three days before his death, her in-laws brought such a healer to the hospital. The healer said they should take him home, which they did, against her wishes. He had wanted to stay, she said. He could not speak anymore, but she had seen the tears in his eyes.

He had been a good man, Farida repeated throughout our conversation. He had confessed to her that he had made one 'mistake', with a sex worker, years before their marriage. It had happened, she added, only because a friend asked him to come along. He had repented. He was fully sincere in his acceptance of death. When he died, she had been reciting the Qur'an for him. He died with a smile on his lips, and everyone present smiled too. The peacefulness of his dying was important to her, as it was for many of my interlocutors in Aceh. Indeed, in Southeast Asia the way of dying is often considered to reflect the moral quality of the person in his/her life (see Shohet 2018b).[12] Possibly, then, narrating the end of life as peaceful was even more important in case of AIDS deaths, to counter the moral stigma of the disease which might otherwise put the morality of the deceased person into question.

Farida told me that she regretted the six months that she had waited with medication. It had been a terrible time. 'I put everything away in my heart', she said, referring to the first months after her HIV diagnosis, 'When I talked with people, I just talked, but meanwhile I felt miserable'. Upon hearing the diagnosis, she had no will to live anymore, explaining, 'I told my husband, I want to die right now. During those six months, there was no happiness at all'. The shame (*malu*) had been the worst, she continued, 'I had lost my confidence standing in front of the children [at school]. How could I teach these children when I was not clean (*polos*) anymore?' Now, after his death, she had told her family about the virus, except for her father who had a heart condition and who, she said, might not be able to bear the knowledge. But she prayed to God that no-one else would find out. She told me repeatedly that she was not afraid of being fired, which was likely to happen if anyone at school discovered her secret, but she did not have 'the courage to face the shame' (*malunya nggak berani*). Like Ita, she had found a way to avert her neighbours' unwanted attention to her monthly travel. In Aceh, widows are considered to be easily susceptible to extramarital affairs – a moral hazard to the community – and therefore often experience limited mobility. Farida told me how she had started to use this and joked with her neighbours that she went to Banda Aceh to look for a new husband; anything to avoid them from suspecting the true reasons of her travel, even if it meant replacing one moral stigma with another.

The support group had made her realize that a good life with HIV was still possible. She had found a friend there with whom she talked about finding a husband. Yet, she said, no-one would talk badly about their husbands – that would amount to *buka aib* (lit. open up what is disrespectable), a grave sin.[13] She only shared 'the small things'. For the rest, she had no-one to *curhat* (pour out one's heart). 'If I cry', she said, 'I can only *curhat* with God'. Her *curhat* with God also kept reminding her of another aspiration, one that Farida referred to more fleetingly, struggling to manage its present necessity while also relegating it to a more distant future. This was the urge to become what she called a *muslima sejati* (a real Muslimah), which she explained as improving her dress and worshipping practice. The HIV diagnosis might be connected. Invoking a different possible cause of her illness in a subjunctive mode (Good and Good 1994), she said that once, after giving birth, she was regularly troubled by a rapidly pounding heart. It was so bad that sometimes she thought she would die. She had had several scans, but the doctors did not find anything wrong. She prayed to God to heal her, and then, from the depth of her heart (*hati kecil*, lit. small liver) came a voice that said 'If I don't [do what I should do], give me an illness that is incurable'. Farida continued her story:

> I didn't want that. It was my *hati kecil* that spoke, but I immediately said, "Please God, don't do that." Yet, when I received the diagnosis of this illness, I suddenly remembered: Perhaps it is because I did not change for God, perhaps that is why I have this illness. It was a promise, but this is what humans are like: When they feel better, they forget.

She said that she felt that she should change, adding, 'But I also first want to marry, so please not yet now … '. She did not explain why exactly marriage plans prevented her from becoming a more observant Muslim – though she may have considered the practice of dating itself incompatible with increasing piety – but expressed ambivalence about the moral dilemma: Becoming a better Muslim was something she should prioritize, yet marriage kept preoccupying her to such an extent that she could not, or not yet, improve her Islamic conduct.[14]

Farida hardly spoke about the virus itself and the spectre of future illness. She only proudly mentioned that during the past year the CD4 levels of her daughter and herself had gone up. Yet, when the call for the evening prayer was already sounding, a sign that we should wrap up, she asked me two questions in response to which I could not give her any certainty. One was whether scientists would find a cure for HIV, the other how long someone who was diligently taking medicine would usually live (*bertahan*, lit. hold out).

A careful navigation of speech and silence ran through Farida's story. She cared through silence, for example through not informing her father of her condition because it could be too burdensome for him.[15] She cared also by not breaking the cultural taboo of talking badly about one's husband, which likely also shaped the story she was telling me. At the same time, Farida encountered limits of speech in the support group, where she could discuss light matters but could not really pour out her heart. Her possibilities of expressing her wishes were also limited by parental authority, painfully claimed by her in-laws during her husbands' dying, as he could both literally not speak and impossibly subvert his parents' wishes.

Farida's deliberate silence work included managing secrecy in the face of social stigma, as she attempted to seemingly lightheartedly divert the attention of her neighbours, colleagues and HIV-negative suitors. This act of pretending was a heavy burden, she told me, as it meant talking nicely 'on the outside', while feeling pain 'inside'. In a way, she underscored the importance of what Unni Wikan (1992, 466) has explained as going 'beyond the words', in order to not equate the speaker's words with her intention and feeling.

The 'inside' knowledge of HIV was threatening. Its public appearance would mean the end of her working life as a teacher, but as a secret it also made it impossible for Farida to be 'clean' in front of her students. She repeatedly said that it caused her to lose her confidence (*PD, percayaan diri*).

The possibility of public disclosure of her HIV status shaped the entire narrative Farida told me, and yet remained largely unspeakable. She stopped telling rather abruptly every time her story tended to move toward this prospect. The fear of ostracization was all too real. Some people in the support group had experienced severe discrimination when their neighbours found out they had HIV. Others told me what they thought might happen: They might be ignored by the community (*dikucilkan*), and even be evicted (*diusirkan*). But when telling her story to me, Farida did not think through such a scenario beyond the problem of losing her job, which was relatively less of concern to her given her middleclass family background. At the limits of the speakable hovered shame (*malu*) – a feeling that she would not have the 'courage to face'. The unbearableness of this feeling is related to social stigma, but as Johan Lindquist (2008) has shown, it also transcends local contexts, invoking the failure not only to live up to expectations in one's direct surroundings, but to the ideals of the nation. Perhaps this failure and its concomitant exclusion from not only social but also Acehnese belonging through bearing, or being, an uncanny presence in society, made *malu* such a powerful emotion for Farida and others living with HIV.

In the space between silence and articulation, Farida's narrative opened up possible alternative futures and pasts. Her reflection on her wish to become a better Muslim spurred the subjunctive mode of recounting her earlier broken religious promise as another possible cause of HIV. Like Ita's story, therefore, her narrative reveals qualities of 'sideshadowing'. Shohet (2018a, 504) explains that, 'In contrast to foreshadowing or backshadowing narratives, whose narrators imagine inevitable futures or foreground hindsight, respectively, sideshadowing narratives embrace contradictory positions and privilege ambivalence and ambiguity'. In sideshadowing mode, Farida opened up the possibility of religious improvement as a 'could-have-been' scenario in the past that might (or might not) have prevented her infection as well as a 'could-be' scenario for the future that hovered at the side of her aspirations to marry. This story, less articulate than the one of infection and marriage she discussed within the support group, fostered an alternative to remake her life in a moral way; a future in which she could live with the invisible virus and the knowledge of not being 'clean'.

Farida's story shows how in a social world that demands – yet also fears – transparency, keeping HIV infection a secret requires navigating social interaction through visibility and narrative. The financing of HIV care through monthly targets and a medical system of monthly mandatory checkups and necessary referral letters demands a certain amount of visibility of patients to health care workers and bureaucrats. Farida's monthly travel to the capital keeps her on the radar of the medical system. Those who do not check in monthly may lose access to medication and end up as missing data, 'lost-to-follow-up'. The target-driven frequent reporting may help to extend biomedical care, but also puts Farida at risk through the suspicious visibility of a young widow's travel. In a place where unseen forces have become a dangerous presence, where people are anxious about appearances that may conceal moral danger, Farida chooses to visibly and narratively highlight the lesser of such moral dangers. She thus emphasizes her sexuality in order to keep her HIV status a secret. The histories that shape anxiety about HIV also affect her own feeling of shame – a shame that puts her belonging to the nation in question and that hovers at the limits of the speakable. Public disclosure, then, is risked by a healthcare system that strives to reach targets through 'transparency' and requires regular long-distance travel. It is both desired and feared by a society that expects ghosts to be present though not yet apparent, and it is the silent threat alongside Farida's articulated future scenarios of marriage and piety. Navigating the need for, and risk of, disclosure requires Farida, like Ita, to carefully balance silence and visibility.

Conclusion

In people's everyday engagement with troubled and troubling worlds, silence comes in many forms along a continuum ranging between articulation and the unspoken or unspeakable (see Weller 2017). Traces of silence manifest in ambiguity, sideshadowing stories, smiles, make-up, whispers, abrupt changes of topic, as well as brave jokes and witty lies – referring to a widow's dating and uncivilized *banci*. The silence work in Farida and Ita's narratives cannot be understood outside of their social and historical contexts, including a heteronormative society, political anxiety about invisible forces, and a global donor- and audit-shaped HIV health care bureaucracy with a (post)colonial legacy of a need for transparency and enumeration. In an epidemic where 'being seen' by society and the state remains a huge social risk, target-driven care that requires names and addresses, and often signatures, results in the further silencing of vulnerable social groups. The (un)spoken, here, demands an understanding of the possibilities and risks of visibility.

At the same time, any strategies of secrecy and nonconscious silences are shaped by the individual's biography and social relations, her hopes, anxieties and aspirations. It was with her mother, whom she protected from hearing her *waria* name, that Ita shared her feeling that death might be approaching, while the thought of being seen as unhealthy – and thereby recognized as a person living with HIV – in her *waria* social world caused her extreme anxiety. For Farida, the once-made promise of religious piety was a subjunctive element in her illness narrative, a story that did not conform to the narratives told in the support group, but that offered a potential future, and perhaps even a way of countering the unspeakable shame of being seen and known as a person living with HIV.

The ways in which silences manifest and emerge subjectively in narrative navigation, form a privileged vantage point for understanding situated socio-historical formations of power and care. Silences in narrative's interstices therefore direct us both to the individual's past and present, and to social discourses and policies – such as those of transparency and visibility, where the need to see and count is continuously confirmed and problematized by the anxiety it causes. In the particular historical context of postcolonial and post-Suharto Indonesia and post-conflict and post-tsunami Aceh, HIV adds a frightening spectre to a multiplicity of anxieties, interlocking 'transparent' bureaucracies of HIV care and societal responses of moral panic in a situation in which people living with HIV need to walk a tightrope of social, psychological and political silences. It is within this social situation and the limits of possibility that its dynamics offer that Ita and Farida articulated certain narratives to silence others, and used and risked their appearance to keep their secret. Here, silence and visibility dynamically intersect on a continuum of articulation and non-articulation.

Notes

1. During 13 months of ethnographic research in 2013–2014 I conducted participant observation with Aceh's HIV support group. I completed thirty in-depth interviews with HIV-positive people in Aceh, and kept in touch with about half of them over a longer period of time. In addition, I attended HIV awareness raising sessions and conducted semi-structured interviews with medical staff, government officials and people working for non-governmental organizations in the health sector. The personal names used in this article are pseudonyms.
2. Retention in treatment is significantly lower when people get diagnosed in clinics where only testing, and no treatment, is available (Januraga et al. 2018).
3. This number had risen to 632 at the end of 2017, see Jawa Pos 6 March 2018 'Jumlah kasus HIV/AIDS di Aceh terus meningkat' https://www.jawapos.com/kesehatan/06/03/2018/jumlah-kasus-hivaids-di-aceh-terus-meningkat/ last accessed 8 July 2020.
4. More recently, another public hospital has started offering medication and medical care for HIV-positive patients.
5. Another powerful example is provided by Patricia Spyer (2002), who, in her work on the conflict in Maluku in the early 2000s, shows how the anxious imagination of the unseen was an integral part of the conflict.
6. See Samuels (2016) for a longer account of Lizzy's last weeks.
7. Dlamini-Simelane and Moyer (2017) have convincingly argued against seeing the 'refusal' to start antiretroviral therapy from a rational-actor perspective. Like the women in their study, the protagonists in this article (Ita and Farida) engage in a complex social navigation in which accessing health care is negotiated in relation to other social priorities and boundaries.
8. In elaborating the concept of narrative navigation (Samuels 2019b) and in my use in of the concept of navigation in this article, I am inspired by Henrik Vigh's (2009) analysis of social navigation.
9. See Tidey (2019) for an account of one extraordinary *waria*, who, with her highly visible work of building a *waria* pesantren (Islamic boarding school) temporarily created a political potentiality for such belonging until her untimely death in 2014.
10. See Thajib (2018) for a discussion on the use and instability of the notion of 'safe spaces' for queer people in Indonesia.
11. Compared to HIV, black magic as a diagnosis may have been much more acceptable to Farida's in-laws, absolving her husband of social stigma and moral responsibility that might not only negatively affect them but also haunt him in the afterlife. At the same time, it needs to be noted that black magic is a very common explanation for all kinds of symptoms, and many patients and families keep trying different trajectories for healing, also if there is a medical diagnosis.
12. The narratives of the 2004 tsunami are interesting in this respect. Though the deaths resulting from the earthquake and tsunami waves could hardly be considered 'good' deaths, many people argued that those who died were martyrs and therefore went straight to heaven, and that God had chosen those whom He loved most (Samuels 2019a). Therefore, these sudden, violent, deaths were generally not considered to reflect the moral position of the deceased persons in life, nor negatively affect them after death.
13. See Van Tilburg (1998) for an elaborate account of encountering silences on taboo topics and the ways in which these silences are meant to protect individuals and groups.
14. David Kloos (2018) shows how religious improvement is a lifelong project for many ordinary Muslims in Aceh. Thus, while younger people often realize that it would be 'good' to become more pious now, they also reason that pious conduct needs to be built over the lifecourse and that they may therefore become more pious when they are older. See Birchok (2019) for an insightful discussion of the dilemmas this may pose to Acehnese who feel they momentarily have to choose between marriage and religious piety.
15. See Han (2012) and Shohet (forthcoming) on the ways in which people care in silence and through silence.

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