9. 'Living in HIV-land': Mobility and Seropositivity among Highlands Papuan Men

Leslie Butt

Introduction: Men and mobility

The lure of Papua as a discrete, politically distinct space has curtailed the study of Papuan mobility, or the impacts of the mobile technologies, peoples, objects and ideas that flow in and out of the province on the indigenous men and women who live there. The tendency has been to privilege the fixity of culture in place, and the site of the production of cultural knowledge itself, over the fluidity and porosity of cultural boundaries and cultural transformations brought about through mobility. The tried-and-true approach, as I have taken in many of my own academic papers, is to assert that particular indigenous tribes of the central highlands region culturally value personal mobility across space, social flexibility across kin lines, and are affected by migrants who have moved into the region, but to then go on to focus analytic attention only on what takes place within the fixed space of their ancestral lands.

This paper explores the critical role of mobility for a particular group of highlands men – HIV-positive men – whose personal trajectories intersect with the mobile flows of viruses, drugs and technologies. In particular, I focus on the intersection between mobile men, the mobility of HIV, and the imported, idealised and highly technological models of HIV diagnosis, testing and anti-retroviral therapy (ART) that have become the new standard for dealing with HIV since the new millennium.

Male mobility has been the focus of HIV/AIDS behavioral interventions for almost two decades, notably under the rubric of MMM, where special risks of HIV transmission were attributed to Mobile Men with Money (UNDP 2004). Within migration streams in Papua, for example, men who leave their highland homes to find work at the well-paying Freeport-McMoran gold and copper mine, in the town of Timika, are seen as more likely to contract HIV than their less affluent, less mobile stay-at-home relatives. While the structural pressures on men to seek opportunities and to engage in risky sexual behavior are well documented, the experiences of the men themselves have been less closely scrutinised. Gender has been recognised as essential to understanding patterns

around HIV infection in Melanesian societies, but women tend to have been more closely scrutinised than men, with men's experiences often left completely unaddressed in interventions (Eves 2010). Men in Melanesia are typically raised in strongly gender-demarcated societies. Communities emphasised warrior training through childhood, and expected aggression, which translates in the present day to engagement with political and personal violence as a way to compensate for insecurities embedded within a Melanesian ethos of masculinity – be it against women, theft or other forms of often brutal violence (Knauft 2011). This masculinity has been described as in crisis, with many rituals designed to affirm male adulthood through recognised rites of passage now destroyed or abandoned (Knauft 1997, 2011). Within Papua, men increasingly leave home and encounter in their journeys alternate models of successful masculine accomplishments, novel displays of wealth or the acquisition of commodities, and the adoption of new forms of marriage, spousal relations and family. In part, men are seeking to counter the emasculating effects of colonialism (Macintyre 2008), as well as their desire to maintain and build a male collectivity (Knauft 2011).

This paper describes what happens to highlands Papuan men after they receive a diagnosis of HIV, how they come to terms with their new status, and their experiences in their home communities when they are seeking treatment. In Indonesia, HIV-positive persons are termed *ODHA* (*orang dengan HIV/AIDS*, or persons living with HIV/AIDS), and upon being so defined by the event of receiving a positive diagnosis, enter into 'HIV-land', the land where the identity of being an *ODHA* comes to dominate personal world views, decisions and actions.¹ Klitzman and Bayer (2003) coined the term 'living in HIV-land' to describe the universe of languages, treatments and protocol that HIV-positive people enter into when accepting a diagnosis. For many men, being an *ODHA* means returning home for treatment (UNDP 2004), where men must engage anew with past traditions and expectations, and where the insecurities and opportunities of new forms of mobility intersect with local community norms and kin expectations. These conditions shape their view on how to deal with their status, and affect who they tell. A desire for continuities and the resumption of routine often characterises men's response to serious personal crises (Becker 1997). Leaving home disrupts the social influence a man has; upon his return, he is less capable of getting care and compassion, or of being able to negotiate social networks, and these deficits have a significant impact on how HIV-positive men negotiate their social relationships. The effects of their decisions, and the scope of their desires, are magnified by an introduced HIV treatment program which is poorly developed, and offers a highly technological, complicated and limited service that demands adherents remain in fixed locales in order to receive treatment.

1 See Boellstorff (2008) for an Indonesian example.

After reviewing the limitations of current anti-retroviral therapy (ART) in highlands Papua, this paper describes the interwoven ways mobile highlands men respond to HIV: by invoking long-standing place-based strategies for dealing with serious illness, including ritual diagnosis, avoidance and isolation; by explaining their condition as a result of their mobility or the mobility of others and the dangers that movement produces; and by engaging with the imported routines and standards of contemporary international HIV treatment protocol despite the frictions and failures of this model when applied in Papua. The particular experiences and strategies of men, distinct in many ways from women's responses, highlight how movement and mobility interweave with longing for closure and acceptance through most aspects of their lives.

Methods

Our research team conducted 32 in-depth interviews with HIV-positive Papuans and 15 interviews with health care workers in urban and peri-urban sites in the central highlands region in 2009 and 2010. I worked with a team of three experienced indigenous researchers from the regional university in Jayapura.² The male interviewers were originally from the highlands, and were able to use their indigenous Yali or Mee language for many of the interviews. All respondents were diagnosed as being HIV-positive at least six months prior to their interviews. All had some experience with medications available for *ODHA*, although their commitment to drug regimens varied widely. I have described women's struggles elsewhere (Butt 2012, 2014), focusing on how racialised identities and gender expectations combine to contain women's aspirations and render them highly vulnerable to stigmatising practices by health workers and community members. Here I provide some comparison between men and women, but focus primarily on men's experiences. In particular, this paper draws from in-depth interviews conducted with 15 HIV-positive indigenous men from the highlands region. They are from the Dani, Lani, Mee, Western Dani and Yali tribes, and their ages range from 15 to 52, with an average age of 25. Overall income and education levels were fairly low. Typical of the highlands, men's income level was higher than women, averaging about \$100/month versus approximately \$50/month, and men were more likely to have finished high school than women. Several men had travelled outside of Papua to pursue higher education elsewhere in Indonesia. With only one exception, all men were interviewed in locations which were different from where they grew

² Researchers Jack Morin, Gerdha Numbery, Andreas Goo and Ibrahim Peyon helped define research questions, brought methodological expertise to research activities, and detailed insights to the analysis of research results. I am grateful to them for their spirited collaboration (see Butt et al. 2010). Research was funded by the Social Sciences and Humanities Research Council of Canada.

up, highlighting high levels of personal mobility as a constant theme among this young cohort, as well as the limited access to therapies which forces those who wished to adhere to drugs to relocate to a town, usually the one closest to their natal home, where clinics have been set up.

Current trends in HIV infection and treatment

The province of Papua has one of the fastest growing rates of HIV infection in Asia. Estimated infection rates range between 3 and 7 per cent of the indigenous population, who make up around 75 per cent of HIV cases (Rees and Silove 2007). HIV has reached generalised epidemic status for indigenous Papuans, but not for migrants to the province. Farmer (1997) has argued that HIV follows along the 'fault lines' of society, reinforcing vulnerabilities and hardening inequities along the lines of income, race and gender. In Papua, HIV infects indigenous males and females in equal number, but drawing the provincial fault lines show there are more indigenous 'housewives', (to use the head of the provincial AIDS commission's term) that is, monogamous Papuan subsistence gardeners, who are HIV positive than Indonesian sex workers, and far more Papuans than Indonesian migrants.

The response to infection appears to be fairly consistent across genders, with nearly equal numbers of Papuan men and women going for tests and initiating a course of ART, although descriptive statistics based on testing patterns in the highlands suggest men are more likely than women to be tested for HIV but less likely to begin a course of ART (Butt 2012; Butt et al. 2010). Because records are so poorly kept, and opt-out testing is not standard either at pre-natal services or at the internal diseases ward at the hospital,³ where many HIV patients end up housed, it is impossible to ascertain whether these numbers reflect actual patterns of HIV infection, testing, or responses to treatment. Most qualified assessors say infection rates are much higher. Health workers employed at the VCT sites set up in the past few years were interviewed about their experiences dealing with *ODHA*. Most stated that *ODHA*, as a rule, do not seek out ART. Several health care workers described the dominant pattern as: 'run back to the village and die'. Health workers estimate that 75 per cent of the men and women they initially speak to about testing respond in this way, and 90 per cent of those who test positive also flee without seeking care. These

3 In 2010, a Family Health International consultant visited the internal diseases ward in a highlands town, where four known patients with HIV were housed in a separate room. The consultant requested that all patients within the ward receive HIV tests as standard procedure. In the inaugural test, 20 patients were tested, with seven of them receiving a positive result.

descriptive statistics signal the clear necessity for more accessible testing, and more rigorous documentation of the demographics of those who drop out of treatment regimens.

Some of the reasons for the gaps in documenting who is receiving testing have to do with disjunctures between the increasingly bureaucratised and standardised international models of intervention, and on-the-ground political and geographical realities. Access to testing, medication and care remains extremely limited (Green 2010). Corruption, lack of follow-through, poor training and an erratic drug supply explain in part why ART has only been available reliably in the province since 2007 and in four urban locations in the highlands – Timika, Enarotali, Wamena and Mulia – really only since 2008. Uptake is low. Preventing mother-to-child transmission programs or prenatal screening was still unavailable as of July 2010. At the same time, managing HIV has become a huge project that involves collaboration between the state, the military, business, mission groups and international NGOs. In 2011, for example, highlands providers of testing and treatment included The Global Fund, UNAIDS, AusAID, USAID, The Clinton Foundation, the provincial health department, the national AIDS Commission, international mission groups, *Médécins du Monde* and World Vision. Systems have improved recently but there is little doubt most Papuans living in rural sites continue to lack access to ARTs, and few Papuan *ODHA* currently take them. Whereas earlier initiatives focused on behavioral modification, now ART dominates. ART travels with 'baggage', protocols and guidelines about who, when and how to provide treatment (Hardon and Dilger 2011: 136; Sullivan 2011) (see Figure 9.1). ART remains hard to access in the highlands because protocol dictates drugs cannot precede labs and training. The protocol makes urban sites a good choice for the highland VCT centres, but it makes the centres inaccessible for anyone more than a 15-minute bus ride away, and challenging for people living even two or three kilometers out of town. Treatment becomes an urban affair, with the elite and educated more likely to get on and stay on regimens. Protocol exacerbates the gap between expectations by these global agencies that an *ODHA* can respond to testing, counselling and treatment in a way that is independent of social context (Eves 2010), and the local, grounded reality, which is that local context strongly shapes behavior, decisions and assessments about quality of treatment (Lepani 2012).

These challenging conditions are compounded by racialised relationships between mostly Indonesian migrant providers and mostly indigenous clients. Associations between contagion and primitivism were redolent in reports and assessments of practices in the new millennium when HIV prevention and treatment initiatives geared up (Munro and Butt 2012). Despite the technocratic nature of new treatment models which would seem to encourage a routinised distribution of medications and testing locations, or perhaps because of it, there is little effort made to integrate political and racial realities into how health employees are trained in Papua. Increasingly, Papuan nurses and peripheral staff are being recruited into VCT work, which is an important step towards

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providing culturally sensitive treatment, but what they learn at training sessions replicates international ideals, allowing for racialised understandings about infection and treatment to endure, on both sides of the equation.

Figure 9.1. Lab materials.

Source: Andri Tambunan.

Figure 9.2. The clinic doctor leads health workers in morning prayer before the clinic opens. Low ranking staff are dressed in white uniforms. The VCT director is second to right in the front row, wearing a white *jilbab*.

Source: Andri Tambunan.

Feelings of mistrust precede and colour the clinical encounter. Counseling and treatment are mostly run by high-ranking doctors and trained registered nurses who are usually Indonesian migrants (see Figure 9.2). Most admissions staff are newly located to the province.

This creates tension along ethnic lines. Papuans and Indonesians tend to racialise each other. The new migrants typically know little about Papuan culture and values, and often choose not to learn about them, acting instead as the 'medical evangelists' who promote a biomedical model (Robins 2009). Many of these employees are quick to criticise Papuans. A Clinton foundation employee described entrenched judgments among his migrant Indonesian colleagues:

[Papuans] getting AIDS is just viewed as come-uppance, as in 'what do you expect from a bunch of fornicating half monkeys? Let them die'. And no, that is not too strong. Of course not all think that way but there is definitely an underlying element of 'Uwww, the savages'.

Papuan health workers criticise back, using equally essentialist terms:

You can't trust [migrants'] feelings. Papuans don't want to go [to their clinics]. Migrants are ignorant. We say when you go there the [migrant] staff use instruments to work on HIV-positive patients and then [migrants] say they have to throw out the tools. Very ignorant. There is bitterness.

When the Papuan health ministry adopts international protocol, the migration of a rigid set of ideas (see Figure 9.3) about treatment legitimates local hierarchies. While services in the province continue to improve as drug distribution becomes more widespread and testing more accessible, there is little doubt that implementing universal access to international drug protocol has resulted in increased inequities around who is infected with HIV and who gains access to treatment (Nguyen 2010), reinforcing the fault lines of society along which HIV in Papua already travels. These conditions make it difficult for *ODHA* to get drugs and to stay on them. In the following section, the experiences of male *ODHA* we interviewed, all of whom at one point attempted to access medications through formal VCT, bring out in subtle ways the disjunctures between what is expected of the *ODHA* with regards to treatment adherence, and the challenges and realities of 'living in HIV-land' for the men who returned home or relocate for treatment.

Figure 9.3. The gloves, clothes and masks required for all health workers giving an HIV test are some of the technologies that clients find unpleasant and that strike fear in many.

Source: Andri Tambunan.

Living in HIV-land: The narrative of contagion

For the 15 male *ODHA* who discussed their status in in-depth interviews, ascertaining the moment of HIV infection appears to play a significant place in coping with their everyday realities of being HIV positive. The narrative they repeat for the interviewer was typically presented in highly stylised, fact-laden depictions. Unlike, for example, questions about age, current housing conditions, or monthly income, where men often offered vague responses, questions about how they thought they contracted HIV elicited detailed, stylised contagion narratives where with only one exception respondents with a great deal of certainty identified the person and the place where they believed they had contracted HIV. The explanations highlight the importance of mobility in men's experiences. For example, one young man who was from the Baliem valley explained how he contracted HIV when he travelled outside his community to the western Dani town of Tiom:

I got this sickness from a woman who already had AIDS. Several friends and I drank hard liquor when we were visiting in Tiom and we invited

a woman who was AIDS positive. When we were drunk we had sex with that woman. That was in 2008 and that woman is already dead. She was from the Kogoya clan and shortly after that I felt sick. In February 2009 the worker from the hospice and Mr Jhon asked me to go to the hospital to test our blood. We went, 8 men and 5 women, to get our blood tested. Then the doctor told us 4 men were positive and 4 women were positive also.

This young man links an episode of sex and drinking which took place only months before testing as the source of his infection. As with most respondents, he selects a sexual episode which occurs away from home and where he has sex with a woman who is from a different tribe or province. Contagion narratives often fit with local political realities and validate and reify pre-existing categories of otherness (Eves and Butt 2008; Lindenbaum 2001). Another young man explained how he contracted HIV from a Manadonese woman while he was away studying in another province:

I contracted this virus while I was studying in Manado at the beginning of 2007. I suspected I was positive because my symptoms were that I was hot, had diarrhea, my body was weak and grew progressively skinnier, and I had prolonged coughing. I got sick because I had sex with a woman from Manado. Right after that I got sick.

In particular, non-Papuan women were seen to be the source of contagion for many. The following explanation by a 52-year-old man to the young male researcher emphasises both how concretely respondents described how they became infected, but also the association for many Papuan men between newcomers to Papua and contagion:

I started to feel sick in 2008 and in 2009 in July I felt truly sick. I had many symptoms, my head hurt, my body was tired, I had diarrhea and my body was getting thin. So I voiced my complaints and was told to go to the hospital in Wamena. Son, I'm sorry to have to tell you this, but I got sick because I strayed [*jalan salah*]. I didn't think like an elder person and I behaved badly all on my own. I had sex with a straight-haired woman. One of those fallen women who work in the food stalls in town. I had sex in 2006 with that woman. Son, I was just going along on my business, at that time I was the assistant to the pastor at my church. I arrived in Wamena and I felt hungry so I went into one of the food stalls. While I was sitting down and eating, that fallen woman with her straight hair came right up to me and opened up her slacks and showed me her genitals. Well, I was not able to contain my lust.

In another case, the young man left home for a trip and came back with the symptoms of HIV after having sex with an Indonesian migrant.

I knew I was infected August 14, 2007. I had been feeling sick for a few weeks, my body was limp and skinny. My head hurt so I went to the hospital right away and got my blood tested. I had been infected two months before. At that time the head from my village came and invited us to a drinking party and we went and got drunk. While we were drunk, we left home and went to the village of Hom-Hom. Then we went into the Bar near the police station in Hom-Hom. In that Bar there were a lot of Javanese women and we had sex with them.

In sum, men were prone to explaining they contracted HIV by having sex with a woman who was not their wife or girlfriend at the time. In addition, the woman was identified as not of the same tribe as the respondent. The sexual episode which the respondent identified as the source of their HIV typically occurred shortly before the respondent fell sick and was tested. Last, the sexual encounter where HIV was contracted occurred while the respondent was away from home. Thus it is not just the migration in to the province which is associated with contagion, the act of departing from home is also linked to risks associated with HIV.

Living in HIV-land: Community and local cures

For Papuan men, futility, frustration and fear characterise life in HIV-land. In societies where social relations of obligation are dominant, and can be profound, secrecy for HIV-positive persons is a highly compelling strategy. Stigma is powerful: the *ODHA* is afraid of being viewed as 'an affront to the moral order' (Keusch et al. 2006), internalising fears of ostracism and avoiding judgments. This fear of judgment, and possible retribution, makes many men afraid to disclose their status to anyone. Our researchers asked both men and women to list the persons they had disclosed their status to: we found men disclosed on average to only 1.6 persons; women to only 1.1 persons. Both these figures are much lower than global norms, where typically people disclose to parents, spouses and siblings early on, and to increasingly large numbers of people as time passes (Klitzman and Bayer 2003; see Zhou 2007).

Unlike many women respondents, who worry constantly about the need to maintain secrecy in the domestic domain, men appear less troubled by the work of hiding their condition, and do not appear to spend time worrying about keeping up appearances. They appear to remain confident in their sense of social worth and in their ability to maintain their secret. A keyword search of respondent discourse around HIV found men tended to frequently reference bodily conditions and symptoms. Concerns about spouses or the household, or emotional words such as 'anger', for example, were rarely used. For men, in

interviews the word most frequently associated with HIV was '*sakit*' (sickness, or sick). For women it was '*takut*' (afraid). As one respondent noted, his work and his social position protected him:

The people believe in me because I am the village head and the village is working the same as usual. The people always do what I ask them to. Because they chose me to be the village head there is no chance they will abandon me now.

Unlike women, for whom secrecy is almost always associated with maintaining comfortable domestic relations, most men emphasised the reason for keeping a secret is to maintain their public social roles as best they are able. As Yebo notes:

I kept my disease a secret because this disease I got is a secret disease. If other people find out then they will broadcast it around and the knowledge will be shared, so this is why I still keep it a secret. Because I am also on the church congregation committee ... For as long as I have been sick I have not gone to the church congregation meetings because I have already sinned. I have already stepped down from my committee responsibilities. But I still go to church to pray or to make offerings of pigs. I used to be active in the church but now I have withdrawn from this work because I feel guilty. But as a member of the congregation I am still active, I have just stopped the committee work. Stopping active work supporting the church is a rupture of my personality that I have to endure alone.

This respondent expresses his concern about loss of social relations by referring in particular to his loss of church-based social status. Most respondents, in contrast, did not emphasise religion, God, or Christian ritual in their coping mechanisms. Some male respondents mentioned praying, but only the above respondent and Yohlua (discussed below) specifically mentioned the impact of their HIV status on their religiosity. In contrast, men overwhelmingly honed in on social networks as the key site of concern. This suggests that social relations are what matter the most to persons who have experienced significant disruption in their lives through an HIV diagnosis.

Another feature of male discourse is one that emphasises agency. Men talk so as to emphasise their personal choices to take ART medications, to try locally produced healing tonics, or not to take drugs at all. For example, one respondent described a ready willingness to go to the hospital for testing, using a language of personal choice:

I knew in my heart I should get checked, and once I found out I made a decision right away to go to the hospital and get medications.

Many men emphasised in the language used in interviews their apparent comfort using health services to get tested, and appear to be willing to listen to health care workers' suggestions on how to adhere to ART:

I shared my HIV-positive status with the religious assistant so he could help me choose the right path. He urged me to take the medications as directed so I can get better. So I have been following the routine until now, without any problems. For as long as I have been taking the medications at the clinic, I haven't had any problems.

However, some men avoid seeking help from VCT centres. Evading all forms of care is a major concern among health workers and HIV advocates, for both men and women, but in particular, men appear to adhere to a culturally grounded response to epidemic disease which guides them in promoting silence and evasion (Wood and Lambert 2008). All cultural groups included in our interviews hold to a set of values which views AIDS as similar to other epidemic diseases. The person often self-secludes, lives alone in the forest, and if the disease is said to be contagious food is placed at a distance from the hut and the person has no social contact. Both the community and the individual expect the person to remove themselves from social relations. For the Yali, for example, AIDS is associated with leprosy, due to the similarity with large oozing, open sores and disfiguring skin conditions. The patient is isolated as the community fears the sick person harbours an epidemic that will eliminate the population. The person is isolated in the forest, and the only one who can visit is the *dukun* (indigenous healer), who may be able to cure the patient. If the patient dies the forest home must be burned. The *dukun* must conduct rituals to protect the close family of the dead person. As researcher Ibrahim Peyon argues (pers. comm.), there are widespread implications of this concept, as it extends to people who do not feel able to be part of community obligations: 'A person who is seen as not useful, dirty, or who has committed wrongs must be removed from the community or relations with that person must be broken. AIDS fits within this category because through their suffering they get stigmatized by the community.'

For example, one respondent from the Dani tribe noted:

In the culture of our village, a person who gets sick is a person you don't sit next to, eat with, work with or live with. They have to build a house just for this sick person all by themselves far away from the village. They build a house in the middle of the forest and there the sick person lives.

Another Lani respondent, speaking in terms of personal responsibility, emphasises his choice to avoid the sanctions and isolation of cultural options:

I haven't told anybody because if I told my father for sure he would get angry. Because my father is a bit harsh in the home so we are all scared.

So, up to now I am the only one who knows. In our [Christian] religion it is not forbidden [to be HIV-positive] but I am the one who is ashamed so I don't want to tell anyone at all, including pastors from my church or anyone. In my culture, someone with AIDS is someone you don't sit with, eat with, work with or live with. We have to make a house for that person far from houses, in the middle of the forest and there the person lives. If they die we have to burn them beside the river and throw their bodies in the river. Because they say this disease can be transmitted... It's like another disease we had before AIDS... it's really similar to AIDS, the person suffers as they get skinny, their body is weak, they have diarrhea and other symptoms. Because of this, in the Lani language we call it '*maluget*', or 'not good disease'.

Male respondents⁴ were also quick to take up indigenous medicines as possible cures for HIV, in particular a popular and expensive fruit tonic made from the pandanus fruit [*buah merah*] in Papua, widely perceived across Indonesia as being able to cure a plethora of illnesses:

When I have money I try and buy some pandanus tonic because I'm starting to feel better. I am certain the tonic can cure me. For example, the symptoms I experienced such as cuts on my genitals are now healed with just one dose. So if I drink the tonic some more then maybe I will be healed, and quickly too.

Before my soul was like a wave, my mood would go up and down, but now that I take that pandanus tonic I am starting to feel better.

In sum, highlands men who are able to obtain care in their home community or who have returned home for care are able to access local treatments that are familiar to them. They are also required to mediate familiar social networks such as church communities or family expectations. On the one hand, the familiar comforts of home offer refuge and succor; on the other hand, familiarity creates new minefields, forcing careful, secretive social relations in order to maintain an active and viable social network. As the following section shows, avoiding stigma is critical but not all are as successful at this task as others. People who have spent time away from their homes find it harder to establish and maintain the successful social relations necessary to shield themselves from stigma and discrimination.

4 No female respondents said they had tried indigenous medicines.

Living in HIV-land: Stigma

Secrecy and denial are acts of refusing to give in to the stigma and hopelessness that seems to accompany HIV diagnosis in Papua. Secrecy allows men to maintain their social status, which in turn is linked to accomplishments achieved through success in negotiating social relations. Men did not expect support from extended family or friends. In fact, active stigmatisation happens often among distant kin and neighbours, and is the form of stigmatisation most *ODHA* worry about. Our research shows that widespread disclosure has serious consequences. In the main, people were afraid to disclose because they were afraid of being discriminated against. We had many respondents express fears like this:

It's hard for me to talk to people about it [my status] because I am scared, scared they won't want to talk to me, or spend time with me anymore, and they will keep away from me. They won't want to eat and drink with me.

Dominant themes were feeling worthwhile as a person by fulfilling their social roles in the family, with regards to food, responsibilities, children, marriage obligations, work and financial contributions. One man put the challenge succinctly:

I don't feel respected, I have an education but I feel I am not useful anymore because I have got this disease.

While most men were able to integrate religion, culture and social relations into their lives in ways they were comfortable with, the case of Yohlua illustrates the horrific implications of stigma when fully enacted. Yohlua's story stands out not just because of the extent of discrimination, but because it illustrates the consequences of mobility on the ability to retain strong social networks in the home community. When Yohlua returned home with HIV, he could not marshal the social support necessary to protect him from the violence of total exclusion, and he relied exclusively on his parents and his faith in God after experiencing complete community shunning.

Case Study Yohlua: 'I am horribly tormented in my soul'

Yohlua was interviewed at age 23, after he returned from the town of Manado in Sulawesi, where he had gone to do a bachelor's degree. While there he fell sick in his fourth semester.

On July 27 2007 I fell very sick and my friends from the highlands that were also doing a bachelor's degree brought me to the hospital. After the doctor told me I was positive for the AIDS disease, my parents sent me Rp. 1.500.000- (US\$150) so I could return to Wamena. Everyone in the villages of Jimugima and Siepketi knew about my status. Their reaction was, they all rejected me and forbid me to live there. After that nobody came to see us in our house, not people from our church and not people from my family. When we moved in, the people who were living there left.

I am horribly tormented in my soul. My parents asked for the people in the church to pray for me but they refused to help us. It was the Catholic church group leader who told everyone in the church that I had AIDS. Then he told all the clan leaders, so everyone who went to church knew. He said 'Yohlua has AIDS so he can't eat, sleep, talk, shake hands with any of us' ... I asked the church group leader to pray for me but they didn't want to. I have already asked them for help three times but they always refuse. So my parents and I say it doesn't matter because God is not blind, God will be the one who will help me.

Yohlua goes on to describe several other episodes of involuntary disclosure, including being barred from the church, being forced to leave another location, and finally finding a refuge away from family and church at the highlands' only hospice. Yohlua's social network is minute, but he perceives the social support he receives from his parents and sister to be very powerful. He also sees God as part of his network of support, drawing out through repeated reference the place of God in replacing the social networks of those who abandoned him.

I ask myself will I die or not. And my parents truly look after me, and they ask the same thing, will Yohlua die or not. My father constantly searches for medications, he conducts diagnosis rituals for ancestor spirits [*adat*] for me. So, for as long as my parents are praying to God for me, my parents get blessings every day and my father's relatives have given money for my medicines ...

Yohlua's invocation of God's forgiveness stands out because he was the only male respondent to strongly articulate the need to rely heavily on God as a source of succor. Yohlua was also the most discriminated against of our respondents. The only other respondent who spoke of relying mostly on God was a woman who was very ill, and had experienced similar levels of discrimination and ostracism as a consequence of her physical appearance.⁵

5 See the case study 'Tina' in Butt (2014).

Yohlua expresses extreme shame. He brings shame not only to himself but to his family, what Davies (2014) calls 'kinships of shame', where feelings of not living up to moral standards extend out to affect the moral evaluation of close kin as well.

I always ask myself why do people talk like that. Will I die or not. Only God knows, I give myself to God only. Then I think it was because I behaved badly. But then I feel very ashamed because all the people of the villages of Waliloa and Dieplowan know and they have all rejected me. I feel guilty because everyone around here also rejects my father so I feel even more guilty. I feel even more ashamed. My shame is not just about me, it includes my parents and my family who also feel shame. We can't walk free because everyone sees us and avoids us so we constantly feel truly ashamed.

In Yohlua's case, extreme shunning and his failure to get a university education appear to exacerbate his shame and by extension that of his family. Because of the family's total ostracism by religious and cultural communities, they are unable to address the shame and provide closure, an act Davies (n.d.; see also Becker 1997) identifies as critical to negating the regulatory effects of kin-wide shame in other parts of Indonesia. Yohlua is also experiencing what Lindquist (2009: 12) describes as a lack of closure common to Indonesian migrants, where the failure to achieve what family and community expect exacerbates feelings of anxiety and uncertainty. Compounded by a poorly organised HIV care system, Yohlua's needs are not being met because he no longer has the acute understanding of local dynamics so as to be able to protect himself and his family, to prevent church leaders from disclosing his case, or to negotiate safe and quiet places where he might live in peace. The only closure available to Yohlua is through a God that is 'not blind' and that will 'help' when no others will, which, I suggest, is a thin and unsatisfactory compensation for what he really wants, which is community acceptance. For Yohlua, living in HIV-land is not about the drugs and the technologies of treatment taking over, but rather about coping with the consequences of partial, incomplete care for *ODHA* that only offers medications in some contexts, and that does not take social contexts and considerations into account except in the most superficial ways (see also Zhou 2007). For Yohlua, living in HIV-land means that shunning and ostracism is absolute. His story highlights his longing for an unattainable return to normalcy, not just to have medications that work but also to be free to be mobile, to return to the village, to be able to pray to God in church together with his community rather than alone with his parents, and to revel in forgiveness, acceptance and inclusion.

Discussion

This paper has explored the impact of mobile flows of people, technologies and viruses on how highlands Papuan HIV-positive men respond to their diagnosis. The stories of Yohlua and his fellow *ODHA* signal the anxieties and challenges men face as they suffer through the consequences of a diagnosis that, for most Papuans, is still a death sentence. Most men we interviewed strive for belonging through retaining social roles, exploring local healing alternatives and evading stigma through secrecy and silence. Anxieties typically identified with Melanesian men, such as around gender and masculinity, do not surface in these accounts (see Knauff 1997). Instead, *ODHA* stories tell us mobility and migration are sites of anxiety, and mobility affects what these men experience and how they understand their current situation. *ODHA* do not look to former regional enemies from times of tribal warfare to explain the transmission of HIV, as non-infected Papuans regularly do (Butt 2008). Instead, *ODHA* look to the women who embody the threat of immigration into the province, and they attribute the virus to them. The enmity Yohlua experienced was that directed at an outsider, someone whose return to the home community set in motion resentment and retribution perhaps for the wider project of having left, of having sought an education elsewhere, or of implicitly challenging some of the social norms of highlands life. Through *ODHA* accounts of personal suffering we can gauge some of the wider issues exacerbated by migration and mobility.

The narratives also tell us how difficult it is for these men to build a life of continuities, to return somehow to something approaching normal. Instead, living in HIV-land forces on the one hand an identity as an *ODHA* that requires secrecy and deception as an everyday feature of life. On the other hand, most *ODHA* we interviewed (as well as the many who evade all forms of treatment altogether and who we were not able to recruit to this study) are denied regular access to viable medications, and the support necessary to remain on them, which might allow for some semblance of normalcy to develop. The political conditions whereby endemic racism and colonial mentalities make their way into health care regimens exacerbate the challenges of getting on drugs and staying on them. Stigma and its vicious effects clearly are partly to blame. However, many respondents do not rely on ART because they cannot. They are victims of the triage logic of the international AIDS 'juggernaut' (Nguyen 2010) that sets up a difficult and demanding drug regimen in remote locales and then fails to provide the full armature of services required for those drugs to be readily available and effective. The triage which is required in order to get drugs out into remote places like Papua means that some people are left out, while those who wish to belong have to aggressively earn their place by strict conformity, tight network management, the strategic deployment of affluence, and otherwise being savvy about the scope of social networks and opportunities

available. Thus the Papuan context supports Fassin's (2007) claim that rather than a normalising, equalising effect, HIV treatments maintain and exacerbate inequalities, and help keep alive the ruptures in the fabric of community.

What these stories ultimately suggest is that fault lines are etched deeply for Papuan men. All the men we interviewed were mobile, travelling within Papua or beyond it, and in their mobility, they have the chance to construct and reconstruct identities and opportunities with a degree of self-consciousness not always available to those who remain put (Williams 2007). But as Lindquist (2009) so carefully documents for other parts of Indonesia, opportunities are not always forthcoming: many mobile aspirants return home empty-handed, the lure of middle-class status unattained. Opportunities are even less readily available for the return Papuan HIV-positive migrant, who adhered to expectations and followed opportunity, and yet who self-consciously returns home requiring care and compassion. Stalwart community networks such as church congregations, and respected public figures such as religious leaders turn out not to be reliable sources of support and forgiveness. The HIV-positive person is compelled to secrecy in these conditions, and for some, HIV also forces a re-envisioning of relations with God. Upon his return the mobile HIV-positive man finds that the mechanisms of discrimination within the nation get replicated in the machinery of HIV health care. Mobility and opportunity have resulted in his relative immobility – he is forced to stay put in order to access care, yet he is unable to strengthen his social relations and expand his networks because, ultimately, the mechanisms of social control within the home community continue to privilege those who have sufficient local cultural knowledge to make it through.

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This text is taken from *From 'Stone-Age' to 'Real-Time': Exploring Papuan Temporalities, Mobilities and Religiosities*, edited by Martin Slama and Jenny Munro, published 2015 by ANU Press, The Australian National University, Canberra, Australia.