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Adding insult to injury: Experiences of mobile HIV-positive women who return home for treatment in Tanah Papua, Indonesia

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Abstract

This chapter explores the personal experiences of mobile HIV-positive indigenous women from Tanah Papua, Indonesia who returned to their home communities in need of social support and treatment. Little is known about the experiences of HIV-positive women returnees in general, and the contours and effects of the moral expectations and boundaries within home communities in particular. This paper draws on close-grained analysis of in-depth interviews and fieldwork conducted between 2009 and 2013 to suggest Papuan women returnees suffer a reduced quality of local network relations, and sustained stigma and gender-based discrimination. We illustrate how the inevitable struggles over belonging that returning young adults face are intensified by the intersection of seropositivity, shifts in the quality of social networks and gendered judgements about mobility. Women returnees are unable to rely on affective networks, and Papua's poorly developed HIV treatment programs magnify these challenges.

Introduction: Mobility and HIV

Increasing numbers of women leave rural communities in search of work, educational or relationship opportunities. Evidence is compelling across the globe that such journeys increase the risk of exposure to HIV (Whiteside 2006; Welaga et al. 2009). Having HIV, in turn, encourages further mobility, including among infected persons who choose to return home for treatment (Clark et al. 2007; Berk et al. 2003; Davis and Stapleton 1991). Despite this strong association between mobility and HIV, there have been surprisingly few studies outside of US contexts exploring the experiences of HIV-positive men and women who return to their home communities. Studies do show that HIV-positive returnees tend to go home because they are seeking support from family, often elderly parents, to go on treatment (Knodel et al. 2010; Carrasco 2011; Elmore 2006). However, little is known about the emotional nature of the relationships between women returnees in particular, and the moral expectations and boundaries of the communities to which they return (compare Salazar and Smart 2011). In communities such as Tanah Papua (a term used by indigenous persons to describe the Indonesian provinces of West Papua and Papua), where high rates of HIV infection add to strong stigmatisation of HIV-positive women, a return may be fraught with unmet expectations on both sides.

In Tanah Papua, as in Melanesia more broadly, the trajectory and growth of HIV has been interwoven with changing patterns of mobility in local moral perceptions. In particular, HIV plays into community-wide understandings of 'risk' behaviour based on mobile women, in which movement is understood as a vehicle for at best unmonitored and at worst unrestrained sexuality, which is understood to result in infection with HIV. This moral script plays into both local evangelical Christian and ancestral understandings of the complex relationship between sickness, morality and sexuality (Wood and Dundon 2014). Christian interpretations view AIDS as the 'scourge' of God; and ancestral logic views responsible sexual behaviour as the only appropriate and effective platform for the continued health and wellbeing of people and their families and villages (for example, Lepani 2012; Dundon 2010).

Regrettably these local moral interpretations have meant that while newer practices of mobility for women have often provided greater access to educational and employment opportunities away from home,

or opportunities for different kinds of sexual experiences and marriage than those usually experienced in home villages, the negative association of mobility with HIV has had a significant impact on the quality of nurture and care available to women when they return home as HIV-positive persons seeking compassion and support. This paper explores the personal experiences of mobilities and of return for adult HIV-positive women from Tanah Papua, Indonesia. Many of the 33 indigenous women we interviewed between 2009 and 2013[1] returned home after finding out about their status in order to seek treatment and care.

We situate the returnees' expectations of family nurture and support within a wider context of migration and its impact on social networks. In other contexts, affective networks help migrants retain positive associations with home communities while women are away from home. Remittances, cell phone contact, social media, webcams, and personal networks help maintain a sense of closeness (McKay 2007, 2012). Home, for many women, is understood as a place of refuge and an idealised site of safe affective networks. Yet for those who remain away, the quality of networks does not necessarily remain intact despite consistent efforts, rigorous routines around social media or diligent efforts by migrants to meet the expectations of home communities (for example, Madianou and Miller 2011). Returning home often means trying to reinvigorate distant and fractured family and extended kin relations. Mallett (2004) suggests home has multiple meanings for the world's migrants, not all of them positive. For mobile Papuan women in particular, the home they left often falls short of their nostalgic imaginings and memories. Further, women who leave are often targets of suspicion associated with their status as mobile persons, especially if their return is viewed as a failure, or if they did not live up to family expectations while away (for example, Lindquist 2009; Williams 2007). Despite opportunities for young Melanesian women to

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1   Leslie Butt and Gerdha Numbery worked with a Papuan research team to conduct a total of 32 in-depth interviews with HIV-positive Papuans in 2009–10 in the central highlands region of the province of Papua. Sixteen of those interviews were with adult women, ranging in age from 18 to 40. In collaboration with local Papuan-run NGOs, Jenny Munro conducted nine interviews with HIV-positive women in Manokwari, in the province of West Papua, in 2011, and eight interviews with HIV-positive women in the highlands of the province of Papua in 2013 as part of a broader project on indigenous experiences of HIV care and education provided by Papuan organisations. Interviews were conducted in Bahasa Indonesia by Munro and Numbery, and were translated by Butt and Munro. All women in all sites were diagnosed as being HIV-positive at least six months prior to their interviews. All the women in all sites were connected to the HIV healthcare system either through a clinic or an NGO; most were either on antiretroviral therapy (ART) or Cotrimoxazole (for treatment of tuberculosis), although their commitment to drug regimens varied widely.

be more mobile than in the past, and the discourses of empowerment that aim to place women at the centre of development, significant tensions surround women's mobility (Wardlow 2006; Spark 2011; Cummings 2008). Mobility away from more conservative, watchful rural sites opens up the possibility of women making decisions, however constrained, about sex and relationships in ways that challenge norms of patriarchal dominance over women's sexual engagements.[2]

Because of these dynamics, this paper explores the particular case of Papuan women (for men, see Butt 2015) asking if, and how, their HIV status compounds the challenges of fitting in that they already face as mobile returnees. We suggest the Papuan women we interviewed suffer a reduced quality of local networks as a result of being away, and they also suffer the stigma and discrimination that are often directed towards women who are viewed as the source of HIV infection and the target of accusations (for example, Hammar 2008). We ask whether the complex negotiations around belonging that young Papuans inevitably face are compounded by local expectations of community solidarity and sociality. Long-term absences may undercut the quality of social networks and the intensity and depth of affective relations.

We further ask how HIV status challenges the work of maintaining social relations on a daily basis once returned home. In Indonesia, HIV-positive persons are termed *ODHA (orang dengan HIV/AIDS*, or persons living with HIV/AIDS), and upon being so defined by a positive diagnosis, enter into 'HIV-land'. Klitzman and Bayer (2003) coined the term 'living in HIV-land' to describe the universe of languages, treatments and protocol that HIV-positive people experience after accepting a diagnosis. Being an *ODHA* means living in HIV-land, but it is a life that must typically be masked. Like other Indonesians, Papuan *ODHA* must engage with kin and community, all while dealing with the health and lifestyle requirements of a demanding treatment regimen (compare Boellstorff 2009). The challenges of returning home are magnified by Papua's HIV treatment program, typical of many resource-constrained communities globally, which is poorly developed. We suggest this confluence of factors exacerbates stigma for all HIV-positive returnees. After briefly reviewing the political context and patterns of HIV infection and treatment in

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2   In Indonesia more broadly, conservative government and Islamic influences also strongly influence gender and sexual space along boundaries of public and domestic domains (Slama 2012: 314; see also Robinson 2009; Davies 2015).

Papua, we describe through the voices of mobile women in three case studies the daily challenges they face. We describe the importance of secrecy and of adopting more traditional social roles because these two strategies allow women to maintain and strengthen the social relations necessary for their wellbeing.

Tanah Papua: Seropositivity and the curtailment of mobility

Tanah Papua has a complex colonial history which distinguishes it from the rest of Indonesia, and shapes the experiences and decisions of mobile people (see Figure 1). Brought under the mantle of Dutch colonialism in the 19th century along with the rest of what is now the independent nation of Indonesia, the geographically challenging western half of the island of New Guinea is made up of approximately one million indigenous Papuans from over 200 distinct language groups. Accelerated development, oppressive political conditions and militarisation characterise ongoing colonialism by Indonesia since a 1969 fraudulent vote found indigenous Papuans coerced into the Indonesian nation (Braithwaite et al. 2010). Many Papuans leave the provinces not, as Indonesia would like, to participate as full citizens in the nation, but in order to acquire education and skills in other Indonesian provinces, which will allow them to return to Tanah Papua able to further the political objective of independence from Indonesia (Munro 2013).

Tanah Papua has one of the fastest growing rates of HIV infection in Asia. Estimated infection rates in 2013 suggest 2.9 per cent of the indigenous population is HIV-positive (Integrated Biological and Behavioral Surveillance cited in Munro 2015a). In Tanah Papua, unlike the rest of Indonesia where intravenous drug use is a common source of HIV infection, HIV is widely understood to be contracted primarily by heterosexual contact. 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. As indigenous migrants travel, they encounter risks to sexual health, such as novel sexual opportunities, novel ways to spend newfound money and exposure to new high-risk lifestyles. In addition, in urban settings dominated by non-indigenous migrants their status as racialised indigenous persons widens 'fault lines' and exacerbates risk.
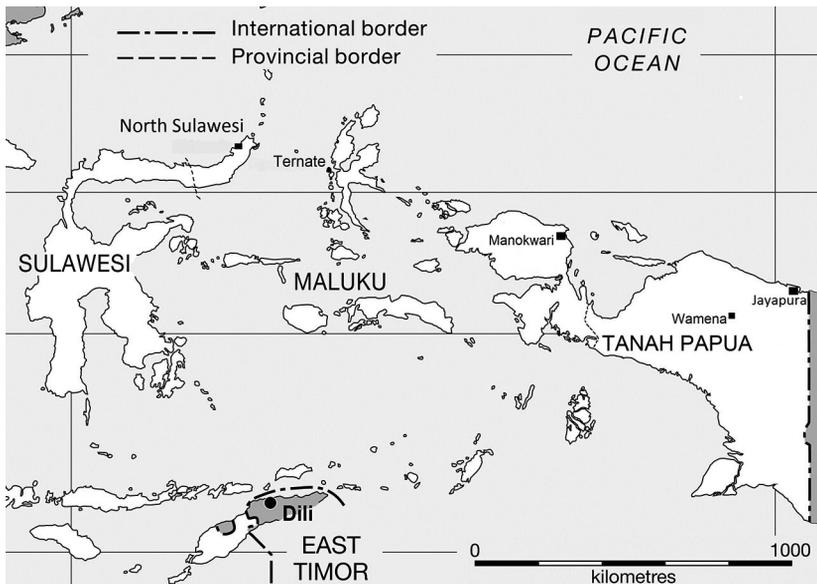
Figure 1: Tanah Papua, eastern Indonesia
Source: © The Australian National University, College of Asia and the Pacific, CartoGIS.

The experience of HIV-positive returnees appears to be shaped more by hopes for compassionate care than by expectations of competent medical care. HIV testing and treatment in Tanah Papua until 2007 was poor or non-existent (Rees and Silove 2007; Butt 2011) and since then has become increasingly available but is erratic and regularly affected by volatile political conditions, stereotypes about indigenous patients and local forms of discrimination (Simonin et al. 2011; Butt 2012; Munro and McIntyre 2016). Testing and treatment travels with 'baggage', namely protocols and guidelines about who, when and how to provide treatment (Hardon and Dilger 2011: 136; Sullivan 2011). In particular, protocol demands treatments remain in a fixed locale. Thus people have to travel to clinics to get drugs and care. For an HIV-positive woman who has returned to Tanah Papua or to her natal town or village for family support, accessing treatment can mean having to relocate from where her family and kin live to one of the larger towns where the few established treatment centres have been set up.

Another challenge to receiving competent care lies in divergent ideas about personal responsibility. Protocol exacerbates the gap between expectations by global agencies that an *ODHA* can respond to testing, counselling and treatment in a way that is independent of social context (Eves and Butt

2008). In Tanah Papua, the grounded reality, where local context strongly shapes behaviour, decisions and assessments about quality of treatment, puts social relations at the forefront. There is a powerful disconnect between what global AIDS narratives promote, namely treatment, and the genre of debates taking place locally, which are primarily grappling with moral, religious and cultural understandings of HIV deservedness (Eves 2012, 2010).

Among local cultural expectations, genealogical ties to land and access to it are strong features of social organisation. These ties must be constantly asserted, and maintained, by using the land, by assisting others in working land or making decisions about land, and by sharing the produce and benefits gained from land. In Melanesian communities sociality is maintained typically through regular displays of gift-giving, nurturance and social assistance; engaging in exchange relations and helping to build and maintain affective networks, which can offer a protective home space for persons who need it. Obligations to family to assist in nurturing the wellbeing of others are constant. When a Papuan woman leaves the region, expectations are raised that she will continue to provide support and reinforce solidarity, with those in the home community often displaying little patience or understanding of the challenges of supporting social relations from afar. Even migration from the highlands to the coast, about 220 kilometres by plane, can have significant consequences for a young woman's ability to maintain strong relations with family at home. At the same time, women face something of a double bind in that while national and local development objectives support education and modernisation, they also emphasise that a woman's most important role is as a sedentary, home-based mother and supportive wife (Nilan 2008).

Thus, for Papuans living in HIV-land, cultural expectations combine with structural limits on treatment to enhance the value of staying in one place. For women, this can mean a complicated dance of trying to overcome the many costs of having left in the first place, engaging anew in local forms of sociality and gift-giving, and making regular visits to a health centre for treatment without disclosing HIV status or disrupting the flows of everyday life and expectations of people around them. The following sections summarise how women we interviewed view their time away and their return home.

Narratives of mobility, contagion and secrecy

Women's explanations and understandings of how they contracted HIV were linked in almost every case to their own mobility. It has become the norm in the past decade for young Papuan women to leave remote rural communities and travel 20 or 30 kilometres by taxi or truck to regional towns to get an education. Spurred on by their parents who want their children to benefit from the province's rapid development, young women leave the village and live in rudimentary student dormitories or with family in town. A fortunate few go on to university, some travelling thousands of kilometres by ferry or by plane to study in other provinces in Indonesia, notably North Sulawesi and Central Java. Away from the protective mantle of close kin, women's sexuality can shift from a set of values primarily created and enacted within rural, clan-based systems that strongly value women's role as the source of brideprice, and as mother to valued offspring, to ones more dominated by individualism, sexual desire and desires for companionate relationships within monogamous marriages (Munro 2012). Being away from home may also introduce a new level of complexity in decisions around sex that women have not previously encountered.

For women, dangers resulting from an HIV diagnosis were local, familial and domestic. Women mainly feared the reactions of those in the home community to which they returned. Women we interviewed were afraid to disclose their status to anyone. Women disclosed on average to only one person, typically the healthcare worker, a spouse or a parent (Butt et al. 2010), a figure that is 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; compare Zhou 2007). The secrecy of these women around HIV is a constructive strategy, a 'generative mechanism for constituting self' that allows them to create safer identities at home (Herdt in Jones 2014: 54). On one hand, secrecy is an effective strategy for managing fragile social relations and for creating confidence. Yet, because secrets by their very nature are made meaningful only because they exist as unspoken within a public domain, their source as a form of protection is always fragile, and secrets are potentially always about to be disclosed. For Papuan women, the choice to keep secrets is a highly compelling, if fraught strategy for coping with moral judgements, avoiding ostracism and remaining socially connected to family (Butt et al. 2010). For women, the home community was an unsafe place where their status had to be guarded very carefully.

Women's sense of their own material worth shaped their determination to keep secrets. Several women said a decrease in their physical wellbeing was a threat to good relations in the family, not just because of brideprice considerations and possibly the loss of culturally significant reproductive capacities, but also because of lost productive capacities as domestic labourers, income earners, market vendors or gardeners. Being criticised for their weak bodies made women feel unworthy, as these statements by HIV-positive women interviewed in 2009 exemplify:

> So now my family is mad, because they say to me you are our capital, now that you are sick all the time, our investment is not paying off.

> My brother says, 'Why are you always sick like this? … you sick like this, it's our loss, we could lose our investment'.

> For four months I have not been taking medicines. When I don't take the medication my body gets thin … I also can't work in the garden much, because I get tired very quickly. I don't have money to buy medicine. My brother says 'there's medicine but it's expensive, five doses is one million rupiah ($US100)' … So my body is getting thin again, and I can't work well. And often my brother says, 'Ayaah, our investment is all gone, right?' According to my brother, in Dani culture we believe the woman is the family's future capital.

In the above statements, interviewees explain that relatives—notably men—are concerned with what they may or may not receive through brideprice payments, and what productive labour has been lost. A groom's family will pay more brideprice for a wife who is educated, who is seen as pious, who performs domestic duties well, and who is seen as sexually innocent—a cornerstone of a 'good' reputation. Walking with or being seen talking to an unrelated male might cause a woman to gain a reputation for being sexually active, especially if she is young and unmarried. Unmarried women with HIV face an additional social imperative to behave and appear 'normal' in order to avoid judgements or questions about their reputation.

If a woman's behaviour deviates from the norm, or is likely to be perceived as deviating from the norm, she is more likely to keep her HIV status a secret. Strikingly, we observed that women who maintain a reputation as a 'good woman' are more likely to confide in their husbands than women who fear their reputations have been damaged. Women with good reputations have earned their husband's trust, and thus hope and expect to receive support from him.

Women also keep secrets because they want to avoid judgements along religious lines. Women whose parents or husbands are involved in church matters were extremely concerned about revealing their status. When women were involved in negotiations around cultural sanctions—for example, brideprice disputes or domestic violence payments—they remained silent to avoid losses to their families and their husbands' families if their status became known. Women also keep secrets to avoid punishment, in particular physical violence at the hands of their husbands or their fathers. Last, but most frequently noted by women, women choose secrecy because they want to avoid ostracism. Ostracism can happen when a family wants to maintain their good name, especially in church circles. If a woman is seen going alone to the clinic or the hospital she may be ostracised: the woman is shunned, limited in her movements and mocked.

As a result, the women we interviewed showed themselves to be experts at hiding their status. When women reveal their status, they tend to do so to persons who are 'safe' in structural terms. For example, we found that women only reveal their status to their boyfriends or husbands if they have already paid the brideprice to their family. Women hide their status by drawing on a strong determination to remain active, contributing members of society. Women work hard to maintain their secrets by increasing their participation in the domestic realm. As one respondent noted:

> They all suspect something, so I have changed my behaviour so I don't lose my husband. Before I got sick, if I did something wrong I always ran away to my mum's house … Now, I am sick but I try really hard to work at selling stuff so that money can come in. I'm afraid, if they know, they won't want to live with me, they won't want to eat my leftover food … So that people don't suspect me, I have to act as though everything is normal. I eat the same as normal with my children and my siblings, I work in the garden like normal, I sell in the market, just like regular healthy people. In the house, my husband treats me like normal. I eat leftover food like everyone else, we sleep together, I breastfeed my child.

Women on medication maintain secrecy about their drug regimen in quite specific ways. Many women obtain medication secretly, by dealing with nongovernmental organisations (NGOs) who pick up and hand out medicines for women, instead of going directly to the hospital. Several women said that if they had to go to the hospital for drugs they would not go. In order to access the medicines, women will lie to husbands

about where they are going. They avoid people they know when they are in places where their status might be revealed (for example, at the HIV treatment centre). They hide medication in a safe, personal space within the home, notably wrapped in plastic in their netbags, and take drugs secretly when everyone is out. They do all of these things to maintain their social role as valued members of their family and community, and to avoid the potential shame and pain of stigmatisation.

As the following case study of one young mobile returnee shows, women who return home for care are required to mediate familiar social networks such as church communities or family expectations. We suggest that for women, secrecy is essential because they rely on social support in the domestic domain to live productive lives. Veronica's[3] story shows how strategic, and demanding, is this work of secrecy.

Case study Veronica: 'This secret is non-negotiable'

Veronica was born and raised in Manokwari, the capital of West Papua province, but her family hails from the island of Biak off the north coast of Papua. Her parents were school teachers and she was a university student until 2011 when her pregnancy began showing. She lived with her boyfriend, a non-Papuan man from Ternate (see Figure 1), whom she referred to as her husband (*suami*) although they were not married. She also lived with her mother, father and her younger sisters in a two-bedroom house in a close-knit neighbourhood full of other people of Biak heritage.

In 2007 while at university in North Sulawesi, she fell sick. She described,

> I got so sick, my skin was full of white spots and boils … I left and went straight home on my own and went to the doctor by myself … I thought it was just a regular disease so I had some medicine but it didn't help, then I went to the tuberculosis room and the doctor said let's just do a complete blood work. He said I had HIV … My reaction was … stress, and fear. But the doctor gave me medicine right away so I felt I was doing something about my sickness.

No one in Veronica's family knew of her HIV status. She was emphatic that the secret must be kept at all costs. 'This secret is non-negotiable (*harga mati*) for me.' Her parents would be so ashamed, she said: 'They heard

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3   All names are pseudonyms.

about someone else who got HIV, and they talked so badly about that person, I can't imagine if they found out their own child was HIV-positive.' She picked up her medication at the Manokwari district hospital and told her family she had a chest infection. Keeping her status a secret most of all, for Vero, involved 'watching my mouth': 'If the neighbours are talking about HIV, I just listen, I just follow along.' Veronica said,

> The hardest thing for *ODHA* is to watch what we say. What would happen if we got engrossed in a conversation and we just said it out loud, 'I've got HIV', well, right away, we better look for somewhere else to stay.

Veronica also described some of the changes in her life and personality she had experienced since her diagnosis, 'I used to get together with friends, take part in activities, but not anymore. I'm afraid they'll find out, or I'll feel like telling them, but I can't if I want to maintain my life, even if it's just like this.'

Veronica and her boyfriend were raising her older brother's child, a girl who was born in 2010. Veronica said that within the family the baby is seen as hers and her responsibility. Vero's parents gave her the task of raising her brother's child while she was studying at university, a move that would seem to contradict cultural and Christian norms concerning marriage and the importance of education. While intrafamily adoption is not uncommon in Papua, handing the baby over to an unmarried university student is unusual, and may be viewed as an attempt by her parents to curb Veronica's mobility and sexual freedoms. Unmarried young women are often expected to look after children in order to teach them to become 'good' wives and mothers, but in Veronica's case it was clear she was given total responsibility, with attendant loss of freedom, increase in responsibility, and heightened gender expectations of conformity and domesticity that come attached with the full-time care of a child. Veronica's father insisted that her boyfriend move into their house as well, so that they might act and appear married, even if they were not. HIV has disrupted Vero's life in that she abandoned her university studies, and depended on performing the hard work of being a housewife and caregiver to earn her keep in the family. Her daily routine revolved around household and childcare duties, including cooking special meals for her ailing father. Social support appears to be most readily obtained through Vero's act of resuming traditional domestic tasks in a fixed locale, and by downplaying personal desires for mobility and education in favour of security.

Punishment, immobility and ostracism

Not all women are as adept at keeping secrets as Veronica. For some, disclosure happens because persons in positions of power reveal a woman's status to the wider community. Disclosure by persons of influence we suggest is more likely to occur when a woman returns home seeking care and support but lacks the deep, ongoing social networks that would make it easier to negotiate relationships and protect secrets. Our second case study profiles a young woman who was unable to keep her status a secret. The fragile nature of HIV care networks surface in this account. What also stands out is the capacity for discrimination at the family level and how judgements about mobility may come to shape how a woman's HIV status is understood.

Case study Nelly: The punishment of loneliness

Nelly was diagnosed with HIV in July 2013 in the regional highlands centre of Wamena, in Papua province, after she became sick while attending university in the coastal capital Jayapura. As Indonesia's easternmost capital, highlanders commonly travel to Jayapura in search of relatives, opportunities or to escape trouble for a while. Although Jayapura's HIV treatment and support facilities are regarded as superior to what Wamena offers, highlanders with ailing health may return home to be close to relatives or to seek traditional medicines. 'I was just about to graduate, I was supposed to graduate in August, but I got sick. I got so skinny and I had diarrhoea. So I came home to Wamena and I didn't graduate', Nelly explained sadly. She described how when she was in Jayapura she struggled financially (*susah uang*) and started hanging out with and having sex with a married man who was older than her. As she said, 'He would call me up and invite me. Then we would get together and have sex, and he would give me money for things. I didn't have money for tuition.'

Nelly described hearing her diagnosis. 'I was scared, I'm going to die … but the nurse said I could take medication and live, and be healthy again.' Nelly lived in a house with her sister and brother-in-law in Wamena where she could access treatment. She told her sister and brother-in-law that she has HIV. 'They know I'm sick and they don't want to talk to me any more … I tried to ask for their understanding, I'm sick right now and I can't work, I can't do anything … I don't have money to even take a pedicab

(*becak*) to the clinic … Sometimes I just stay alone in my room, hungry.' Nelly also noted, voice quivering, that her sister refused to take her to the clinic. She recalled, 'The nurse asked me, "Nobody accompanied you!?"'

Nelly is clearly devastated by her unfortunate return to Wamena just weeks before she was to graduate. Nelly had strongly embraced the aspirations embedded in the very act of leaving home, including her hopes for personal success, her family's hopes, as well as the expectations of the wider community (Lindquist 2009; Munro 2015b). Many young women who start university do not get past their initial year or two before they get married and/or pregnant, usually to a fellow university student. That Nelly managed to get so far into her degree, without actually finishing, perhaps contributes to the rejection, lack of compassion and ostracism her sister and brother-in-law displayed towards her upon her return. When Nelly went away to study in Jayapura, like many students, she was expected to live independently from her family, to protect herself, to stay on the moral path and to achieve results amidst trying conditions. That she returned HIV-positive and ill means Nelly is not able to gain employment and is likely seen as having no prospects for marriage. Nor is she able to perform domestic duties because she is too ill. There is the shame and stigma of HIV, but there is also the shame of going back home in a worsened personal situation. When her family refused to take her to the clinic, they forced her to go alone: to do anything alone, be it stay in a room in the house or go out in town, is a particularly strong expression of disapproval and form of exclusion in a place where people rarely eat, sleep or walk around on their own. Her ostracism on the domestic front drives home the fragile balancing act young women must maintain in order to be mobile and modern while at the same time establishing their status as grounded, community-oriented 'good women'.

The final case study highlights the heartache of having secrets exposed to the wider community. Tina's story reinforces how women who have spent time away from their homes find it hard to establish and maintain the successful social relations necessary to shield themselves from stigma and discrimination when they return.

Case study Tina: 'Hey kids, don't play near her'

Tina was born and raised in a rural district near Wamena, but she moved with her family to attend high school in Wamena for two years. She married a local man and had twin girls at a young age, living continually with her parents and eventually divorcing her difficult and irresponsible first

husband. Tina promptly married again, to a soldier who accused her of infidelity when she travelled to a dance in another region without him. Tina was heartbroken at his constant abuse, leaving her children behind to travel alone to the coastal capital of Jayapura for several months.

After falling sick while on the coast, she returned home to Wamena a year later and underwent HIV tests at her father's insistence. Her father was a trained healthcare worker and had learnt about the symptoms of HIV at a training workshop in 2007. She was diagnosed with HIV, and received moderate support from her family who knew about her status from the outset because the lab worker had communicated results to Tina and to Tina's father, who then told the remaining members of their household. Both her parents and her older sister humanely provided nurture and care, cooking foods she could eat and helping her with medications. By and large her family accepted the situation: 'My father wasn't mad at me, he only thought, "this is my daughter, my young daughter, she likes to go out and about (*jalan-jalan*), she doesn't like to listen to her parent's advice, she doesn't look after herself." But my mother, she was very angry at me.'

As is typical of others living in HIV-land, Tina was immersed in the life of her medications, carefully naming and itemising the drugs she had to take and their side effects. But her regular trips to the health centre and her obvious physical symptoms of extreme weight loss and skin lesions led to many questions in the community. Because of a healthcare worker's disclosure, Tina's status became public knowledge. As a result, neighbours and extended kin have shunned her, and her former husband's family in particular have actively marginalised her.

While her father's position in the health sector made it impossible to truly shun her, as he is a person of some renown in the community, she had nowhere else to stay. Living in her father's house in health worker housing in the centre of town, she was unable to guard her secret from the wider community. Similarly, because she was too sick to care for herself, she was unable to retreat to an isolated rural home and withdraw herself, a respected local response to illness. In town, in front of neighbours, she was exposed to constant, overt stigmatisation. 'The worst are the neighbours', said Tina. She would sit outside and the neighbours would come out of their house and just stare at her. They would then shoo the children away, Tina recounted: '"Hey kids, don't play near her", they say, or "Why are you just sitting there?" so the kids don't play in front of my house, it really hurts my feelings.'

Tina said the health worker who did her blood test was from the same clan as her. He helped her choose her foods and gave advice on staying healthy. But inadequate training around confidentiality led to him disclosing her status to many others within the wider community.

> He makes it really clear he doesn't care anything about me. When he comes by he just looks at me with half an eye, like he is afraid to come into my house and talk to me. It makes me very sad … So I sit in the house only, if I ever leave the house people from around the house are afraid to see me, they run away from me. If I am sitting here and the health worker walks by, he ignores me. He looked after me at the clinic, but now he just gives me a dirty look.

Tina's case reinforces the importance for women of having a safe domestic space they can count on. Treatment itself reimposes constraints on women's mobility, and, as enacted through local health workers, also becomes a form of moral recovery through domestic confinement and compliance with gender norms. Confinement and compliance are, in local understandings, contrasted with Tina's former preference to 'go out and about' (*jalan-jalan*), or to travel alone to the coast, both of which are associated with a negative and promiscuous sexuality.

Discussion: Living in HIV-land

This paper has explored the challenging experiences of women who return to their home communities with HIV. Rather than home being a place of solidarity and refuge for care and HIV treatment, women may be stigmatised, ostracised, denied support or forced into secrecy to avoid these eventualities. Family commitment cannot be guaranteed. Stalwart community networks such as church congregations, and respected public figures such as healthcare workers, may not turn out to be reliable sources of support and forgiveness. The case studies of Veronica, Nelly and Tina signal the anxieties and challenges Papuan women face as they suffer through the consequences of a diagnosis that, for most Papuans, is still a death sentence. Their stories tell us that choosing to leave their homes has long-term negative effects when they return with HIV. All our respondents strived for belonging through retaining or re-establishing social roles that had been transformed by their 'failed' mobility. The social roles they could achieve were further dependent on whether or not their HIV diagnosis was kept secret. The management Veronica and Nelly deploy to maintain their social networks *and* their secrets fill their days.

The enmity Tina and Nelly experienced was of that directed at a relative 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 or opportunities elsewhere, or of implicitly challenging some of the social and sexual norms of local social life. In other words, being a returning migrant is hard, being a female return migrant is harder still. Being *ODHA* and at 'home' just adds insult to injury.

Women's experiences of HIV and mobility are best understood in relation to their ventures outside the domestic sphere and away from the guardianship of close kin. The women in this paper were not only spatially mobile but also socially mobile—they made sexual choices, relationship choices and life choices—and the subsequent treatment they received from others around them reflects not just the stigma of HIV but ambivalent views of women's mobility in spite of empowerment discourses, middle-class aspirations and pro-development conditions. When women's status is in transition, the violence against them and efforts to control or stigmatise their behaviour are at their peak (Spark 2011). Veronica, Tina and Nelly left home to seek opportunities elsewhere, in pursuit of education, broader social networks and other opportunities. Negative or at best ambivalent views of young women's mobility contribute to the vulnerability that they ultimately experience when they return home HIV-positive. Furthermore, if low social support is a determinant of HIV risk in other contexts (Weine and Kashuba 2012), then mobile women in Papua are already more vulnerable to HIV transmission in the first place because their mobility is almost certainly going to be judged as inappropriate or will cause them to lose kin networks. The women's experiences also affirm the findings of Olwig (2012) that women migrants often feel compelled to narrate their mobility in positive moral and gendered terms, and as deserving of social recognition by the community in an effort to deflect preconceived negative attitudes, and, we also suggest, to protect social support and kin networks.

Living in HIV-land forces an identity as an *ODHA* that requires secrecy and deception as an everyday feature of life. The mobile women we interviewed have the chance to construct and reconstruct identities and opportunities with a degree of self-consciousness not always available to those who do not leave their home villages and towns. But as Lindquist (2009) 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 women. The mere act of requiring care, rather than giving it, may test local gender expectations where women are the caregivers and expected to sacrifice their own well-being.

Mobility and opportunity have resulted, ultimately, in immobility. Papuan women are forced to stay put to access care where stigma is perpetuated, yet are unable to strengthen social relations, or invoke a caring support network, because the mechanisms of social control within the home community privilege those who remained in place and built local connections and solidarities. The divergent experiences of Nelly, Veronica, Tina and others, and the central importance of secrecy in their everyday lives, challenge simplistic notions that a strong Melanesian safety net based on traditional kinship systems will somehow override the stigmatising potential of HIV. The cultural aspirations for belonging and solidarity of our respondents are, however, not diminished. The denial of forms of sociality they have previously enjoyed in their communities is particularly hurtful. At the same time, based on their experiences, we ask how much not being able to access support at home is a cultural phenomenon, and how much it relates to the broader formulation of HIV responses, which have neither engaged Papuan values nor created space for conversations about how Papuans might, or would like to, support *ODHA* in their families and communities. Dominant responses to HIV in Tanah Papua have tended to overlook the complexity of Papuan lives, gender relations and inequalities, not least because Papuan research, leadership and experiences have been overshadowed by a politically motivated preference for simplified and standardised international HIV policies and interventions (Munro and Butt 2012). To improve care and support for HIV-positive Papuan women, especially return migrants, local moral judgements *and* inflexible HIV strategies need to be challenged. Papuans are already acknowledging and critically reflecting on these complexities, but they would benefit from more partners in development agencies and government who support efforts to build appropriate local treatment and support. Appropriate public health interventions need to view HIV-positive women less in terms of their adherence to treatment protocols and more as persons whose survival may depend on social support. They will need to tackle the hard truths that existing systems of social support may exacerbate problems of stigma and secrecy, and may contribute significantly to the challenges of accessing adequate HIV treatment and effective care for the deserving Papuan women who have returned home looking for it.

Acknowledgements

References

Berk, ML, Schur, CL, Dunbar, JL, Bozzette, S & Shapiro, M 2003, 'Short report: migration among persons living with HIV', *Social Science and Medicine,* vol. 57, no. 6, pp. 1091–1097. doi.org/10.1016/S0277-9536(02)00487-2

Boellstorff, T 2009, 'Nuri's testimony: HIV/AIDS in Indonesia and bare knowledge', *American Ethnologist,* vol. 36, no. 2, pp. 351–363. doi.org/10.1111/j.1548-1425.2009.01139.x

Braithwaite, J, Braithwaite, V, Cookson, M & Dunn, L 2010, *Anomie and violence: non-truth and reconciliation in Indonesian peacebuilding*, ANU E Press, Canberra.

Butt, L 2011, 'Can you keep a secret? Pretences of confidentiality in HIV/AIDS counseling and treatment in Eastern Indonesia', *Medical Anthropology,* vol. 30, no. 3, pp. 319–338. doi.org/10.1080/01459740.2011.560585

Butt, L 2012, 'HIV/AIDS testing, treatment and the sedimentation of violence in Papua, Indonesia', *Western Humanities Review,* vol. 66, no. 3, pp. 35–57.

Butt, L 2015, 'Living in HIV-land: mobility and seropositivity in highlands Papua', in M Slama & J Munro (eds), 'S*tone age' to 'real time': exploring Papuan mobilities, temporalities and religiosities*, ANU Press, Canberra, pp. 221–242.

Butt, L, Morin, J, Numbery, G, Peyon, I & Goo, A 2010, *Stigma and HIV/AIDS in highlands Papua*, Pusat Studi Kependudukan, Jayapura.

Carrasco, LN 2011, 'Who cares? HIV-related sickness, urban–rural linkages, and the gendered role of care in return migration in South Africa', *Gender and Development,* vol. 19, no. 1, pp. 105–114. doi.org/10.1080/13552074.2011.554028

Clark, SJ, Collinson, MA, Kahn, K, Drullinger, K & Tollman, SM 2007, 'Returning home to die: circular labour migration and mortality in South Africa 1', *Scandinavian Journal of Public Health,* vol. 35, 69 sup, pp. 35–44.

Cummings, M 2008, 'The trouble with trousers', in L Butt & R Eves (eds), *Making sense of AIDS: culture, sexuality, and power in Melanesia*, University of Hawai'i Press, Honolulu, pp. 133–154. doi.org/10.21313/hawaii/9780824831936.003.0008

Davies, SG 2015, 'Surveilling sexuality in Indonesia', in LR Bennett & SG Davies (eds), *Sex and sexuality in Indonesia: sexual politics, diversity and representations in the Reformasi era*, Routledge, London, pp. 30–61.

Davis, K & Stapleton, J 1991, 'Migration to rural areas by HIV patients: impact on HIV-related healthcare use', *Infection Control and Hospital Epidemiology*, vol. 12, no. 9, pp. 540–543.

Dundon, A 2010, 'AIDS and "building a wall" around Christian country in rural Papua New Guinea', *The Australian Journal of Anthropology,* vol. 21, no. 2, pp. 171–187. doi.org/10.1111/j.1757-6547.2010.00077.x

Elmore, K 2006, 'The migratory experiences of people with HIV/AIDS (PWHA) in Wilmington, North Carolina', *Health and Place,* vol. 12, no. 4, pp. 570–579. doi.org/10.1016/j.healthplace.2005.08.009

Eves, R 2010, 'Masculinity matters: men, gender-based violence and the AIDS epidemic in Papua New Guinea', in V Luker & S Dinnen (eds), *Civic insecurity: law, order and HIV in Papua New Guinea*, ANU E Press, Canberra, pp. 47–80.

Eves, R 2012, 'Resisting global AIDS knowledges: born-again Christian narratives of the epidemic from Papua New Guinea', *Medical Anthropology*, vol. 31, no. 1, pp. 61–76. doi.org/10.1080/01459740 .2011.594122

Eves, R & Butt, L 2008, 'Introduction: gender, sexuality and power in Melanesia', in L Butt & R Eves (eds), *Making sense of AIDS: culture, sexuality, and power in Melanesia*, University of Hawai'i Press, Honolulu, pp. 1–23. doi.org/10.21313/hawaii/9780824831936.003.0001

Farmer, P 1997, 'Social inequalities and emerging infectious diseases', *Emerging Infectious Diseases,* vol. 2, no. 4, pp. 259–269. doi.org/ 10.3201/eid0204.960402

Hammar, L 2008, 'Fear and loathing in Papua New Guinea', in L Butt & R Eves (eds), *Making sense of AIDS: culture, sexuality, and power in Melanesia*, University of Hawai'i Press, Honolulu, pp. 60–79. doi.org/10.21313/hawaii/9780824831936.003.0004

Hardon, A & Dilger, H 2011, 'Global AIDS medicines in East African health institutions', *Medical Anthropology,* vol. 30, no. 2, pp. 136–157. doi.org/10.1080/01459740.2011.552458

Jones, GM 2014, 'Secrecy', *Annual Review of Anthropology*, vol. 43, no. 1, pp. 53–69. doi.org/10.1146/annurev-anthro-102313-030058

Keusch, G, Wilentz, J & Kleinman, A 2006, 'Stigma and global health: developing a research agenda', *The Lancet,* vol. 367, pp. 525–527. doi.org/10.1016/S0140-6736(06)68183-X

Klitzman, R & Bayer, R 2003, *Mortal secrets: truth and lies in the age of AIDS*, Johns Hopkins University Press, Baltimore.

Knodel, JE, Hak, S, Khuon, C, So, D & McAndrew, J 2010, *A comparative study of antiretroviral therapy assistance from parents and family members in Cambodia and Thailand*, Population Studies Center, University of Michigan, Ann Arbor.

Lepani, K 2012, *Islands of love, islands of risk: culture and HIV in the Trobriands*, Vanderbilt University Press, Nashville.

Lindquist, JA 2009, *The anxieties of mobility: migration and tourism in the Indonesian borderlands*, University of Hawai'i Press, Honolulu.

Madianou, M & Miller, D 2011, 'Mobile phone parenting: reconfiguring relationships between Filipina migrant mothers and their left-behind children', *New Media and Society,* vol. 13, no. 3, pp. 457–470. doi.org/10.1177/1461444810393903

Mallett, S 2004, 'Understanding home: a critical review of the literature', *The Sociological Review,* vol. 52, no. 1, pp. 62–89. doi.org/10.1111/j.1467-954X.2004.00442.x

McKay, D 2007, '"Sending dollars shows feeling" - emotions and economies in Filipino migration', *Mobilities,* vol. 2, no. 2, pp. 175–194. doi.org/10.1080/17450100701381532

McKay, D 2012, *Global Filipinos: migrants' lives in the virtual village,* Indiana University Press, Bloomington.

Munro, J 2012, '"A diploma and a descendant!" Premarital sexuality, education and politics among Dani university students in North Sulawesi, Indonesia', *Journal of Youth Studies*, vol. 15, no. 8, pp. 1011–1027. doi.org/10.1080/13676261.2012.693592

Munro, J 2013, 'The violence of inflated possibilities: education, transformation and diminishment in Wamena, Papua', *Indonesia,* vol. 95, pp. 25–46. doi.org/10.1353/ind.2013.0008

Munro, J 2015a, '"HIV is our problem together": developing an indigenous-led response to HIV in Tanah Papua', SSGM In Brief 2015/5, State, Society and Governance in Melanesia Program, The Australian National University, Canberra.

Munro, J 2015b, '"Now we know shame": malu and stigma among highlanders in the Papuan diaspora, in M Slama & J Munro (eds), '*Stone age' to 'real time': exploring Papuan mobilities, temporalities and religiosities*, ANU Press, Canberra, pp. 169–194.

Munro, J & Butt, L 2012, 'Compelling evidence: research methods, politics and HIV/AIDS in Papua, Indonesia', *The Asia Pacific Journal of Anthropology,* vol. 13, no. 4, pp. 334–351. doi.org/10.1080/14442213.2012.694467

Munro, J & McIntyre, L 2016, '(Not) getting political: indigenous women and preventing mother-to-child transmission of HIV in West Papua', *Culture, Health and Sexuality,* vol. 18, no. 2, pp. 156–170. doi.org/10.1080/13691058.2015.1070436

Nilan, P 2008, 'Youth transitions to urban, middle-class marriage in Indonesia: faith, family and finances', *Journal of Youth Studies*, vol. 11, no. 1, pp. 65–82. doi.org/10.1080/13676260701690402

Olwig, KF 2012, 'The "successful" return: Caribbean narratives of migration, family, and gender', *Journal of the Royal Anthropological Institute*, vol. 18, pp. 828–845. doi.org/10.1111/j.1467-9655.2012.01794.x

Rees, S & Silove, D 2007, 'Speaking out about human rights and health in West Papua', *The Lancet,* vol. 370, pp. 637–639. doi.org/10.1016/S0140-6736(07)61318-X

Robinson, K 2009, *Gender, Islam and democracy in Indonesia*, Routledge, London.

Salazar, NB & Smart, A 2011, 'Anthropological takes on (im)mobility', *Identities,* vol. 18, no. 6, pp. i–ix. doi.org/10.1080/1070289X.2012.683674

Simonin, A, Bushee, J & Courcaud, A 2011, 'Social, cultural and political factors in the design of HIV programmes with Papuan highland communities', *Culture, Health and Sexuality,* vol. 13, supp. 2, pp. 185–199.

Slama, M 2012, '"Coming down to the shop": trajectories of Hadhrami women into Indonesian public realms', *The Asia Pacific Journal of Anthropology*, vol. 13, no. 4, pp. 313–333. doi.org/10.1080/14442213.2012.699089

Spark, C 2011, 'Gender trouble in town: Educated women eluding male domination, gender violence and marriage in PNG', *The Asia Pacific Journal of Anthropology,* vol. 12, no. 2, pp. 164–179. doi.org/10.1080/14442213.2010.546425

Sullivan, N 2011, 'Mediating abundance and scarcity: implementing an HIV/AIDS-targeted project within a government hospital in Tanzania', *Medical Anthropology,* vol. 30, no. 2, pp. 201–221. doi.org/10.1080/01459740.2011.552453

Wardlow, H 2006, *Wayward women: sexuality and agency in a New Guinea society*, University of California Press, Berkeley.

Weine, SM & Kashuba, AB 2012, 'Labor migration and HIV risk: A systematic review of the literature', *AIDS and Behavior*, vol. 16, no. 6, pp. 1605–1621. doi.org/10.1007/s10461-012-0183-4

Welaga, P, Hosegood, V, Weiner, R, Hill, C, Herbst, K & Newell, ML 2009, 'Coming home to die? The association between migration and mortality in rural South Africa', *BMC Public Health,* vol. 9, no. 1, p. 193. doi.org/10.1186/1471-2458-9-193

Whiteside, A 2006, 'HIV/AIDS and development: failures of vision and imagination', *International Affairs,* vol. 82, no. 2, pp. 327–343. doi.org/10.1111/j.1468-2346.2006.00534.x

Williams, CP 2007, *Maiden voyages: eastern Indonesian women on the move*, Institute of South-east Asian Studies, Singapore.

Wood, M & Dundon, A 2014, 'Great ancestral women: sexuality, gendered mobility, and HIV among the Bamu and Gogodala of Papua New Guinea', *Oceania,* vol. 84, no. 2, pp. 185–201. doi.org/10.1002/ocea.5054

Zhou, YR 2007, '"If you get AIDS … you have to endure it alone": understanding the social constructions of HIV/AIDS in China', *Social Science and Medicine,* vol. 65, pp. 284–295. doi.org/10.1016/j.socscimed.2007.03.031