

Stigma and HIV/AIDS in Highlands Papua

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1. Executive Summary

The province of Papua has the highest incidence of HIV infection per capita in Indonesia. In the remote central highlands of the province, managing HIV has become a huge project that involves getting basic information out to isolated communities, providing access to testing and counselling, and offering medications to manage HIV to those few who do get tested. Rates of infection have been often estimated at 2% of the general population, but among indigenous highland populations, new estimates suggest around 7% are HIV-positive. Access to anti-retroviral treatment (ARV), support and care is extremely limited, despite concentrated efforts in the past two years to train staff and improve drug distribution and access. Only 45 people are currently on ARVs in the Jayawijaya district, even though over 800 people have tested positive for HIV, an uptake of only six percent. Only 7 out of 64 HIV-positive persons are on ARVs in Enarotali in the Paniai district, an uptake of only 10%. Services remain bedevilled by cavalier care, lack of follow-through, and poor training. The drugs available to treat HIV are supposed to be free but often are not. Drug supply is erratic. Levels of disinformation remain high in many parts of the highlands. Many communities are already experiencing high levels of HIV infection, but awareness about HIV remains low. The potential for misunderstandings, misinterpretations, and for stigmatizing practices in the highlands region is very high.

The goal of this research was to describe the experiences of indigenous persons living with HIV and AIDS in highlands Papua (the acronym ODHA is used to refer to indigenous persons living with HIV/AIDS in this report), primarily in the Jayawijaya district. We give particular emphasis to the links between gender, health care, and how current conditions -- economic and political -- might affect experiences of stigma. This project questions:

- a. What are the experiences of stigma and discrimination for HIV-positive indigenous persons in highlands Papua?
- b. How does this experience differ by gender?
- c. In what ways do current conditions, especially health care, affect the experiences of stigma and discrimination?

There has been no research on experiences of living with HIV/AIDS in the highland district, and very little within Papua as a whole. This report summarizes the results of original qualitative research conducted in 2009 in Papua, Indonesia. In-depth interviews and observations were conducted between May and November in two highland locations; the town of Wamena, in Jayawijaya district, and the town of Enarotali, in Paniai district. A total

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of 28 ODHA were interviewed for this project. The Dani, Yali, Mee and the Lani are the primary groups described. Eleven health care staff involved in the provision of counselling, testing and treatment in Wamena were also interviewed. Participant observation was conducted throughout. The goal was to describe experiences and conditions of ODHA as a whole that can be generalized to represent the experiences and needs of HIV-positive indigenous persons in the highlands.

Research Results

HIV-positive persons and Stigma:

- The ages of the 28 ODHA interviewed for this study range from 15 to 52, with an average age of 25. Fifteen of the 28 respondents were women, and 13 were men. Most respondents had low or medium levels of income, but several had secure positions with a fixed salary. Education levels were overall low.
- All respondents were HIV-positive and had undergone testing to confirm their status. All but 3 respondents were currently on ARV therapies, provided from five separate health care locations. The three who were not on ARV therapies were experimenting with an indigenous herbal remedy made from local forest medicines.
- All respondents described strong experience of stigma. Some respondents described overwhelming experiences of stigma and discrimination, such that they were persecuted and unable to live a peaceful life. Other respondents described moderate levels of stigma, which caused significant modifications in their behaviour but did not completely alter their social habits.
- All of the respondents but one had chosen to tell at least one person about their HIV status. Both men and women consistently contained their disclosure to close family members – usually husband or wife, parents, or sister or brother. Only two respondents said they had voluntarily told extended family members, and no one had voluntarily revealed their status to their friends. Their overwhelming reason for not disclosing their status was fear of stigmatization.
- Respondents described stigmatizing practices as coming from many different sources, suggesting the roots of stigma lie in close cultural practices as much as they do in larger macro-economic or political conditions. In particular, respondents clearly noted stigma arose from: involuntary disclosure of their status by others; involuntary disclosure by a person in a position of power such as a church leader or a health care worker; errors in the provision of health care including the violation of confidentiality; lack of access to ARVs or non-confidential access; discrimination at the level of extended kin and community; cultural ideas and practices surrounding serious illness; cultural values around death and dying; cultural values of ostracism; political conditions leading to racism; absent or inadequate health care; delays in the provision of basic services; and self-stigmatization.

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- Both men and women said they mostly received support from their close families, although some families did not support their ODHA relatives. However, both men and women said they had little expectations of social support from extended family, friends, and community. Great care was taken to avoid disclosing to extended family and clan members. Active stigmatization appears to occur more frequently among distant kin and neighbours than close family members.
- Widespread disclosure has serious negative repercussions for both men and women in highlands Papua. Disclosure that occurs by people in positions of power or authority appears to be particularly damaging for an ODHA. Stigmatization is overwhelming when a person's status is made public by a church leader, or when a health care worker publicly tells the community about a person's status.
- Cultural values affect responses to stigma to a certain extent. Among highland peoples, social withdrawal is a sanctioned cultural response to a serious illness that is seen to be contagious. The person often self-secludes and lives alone in the forest. As a result, social withdrawal and isolation are legitimate, and common, responses to an HIV diagnosis. The ODHA does not seek out ARV therapies. Several health care workers described the dominant pattern as "run back to the village and die." Health workers estimate that 75% of the people they initially speak to about testing respond in this way, and 90% of those who test positive also flee without seeking care. This is a large gap in the provision of care, and signals an urgent need to provide adequate services to meet the needs of this population.

Gender and Stigma:

- Men are more likely to access HIV testing than women. Men make up 60% of those undergoing HIV tests in Wamena's three test locations.
- Men are less likely to access ARV therapies than women.
- Experiences of stigma are roughly similar for both men and women. Dominant themes for both genders was feeling stigma if they were unable to be worthwhile as a person by fulfilling their social roles in the family, with regards to responsibilities, children, marriage obligations, work and financial contributions.
- There are differences in self-stigmatization (negative values that the target person comes to believe are true of him or herself) between men and women. Overall, although women appeared to disclose their status slightly more than men, they were less able to contain the negative effects of disclosure. When women were the targets of stigma and discrimination, they were very strongly targeted. Thus, women display a much greater concern with maintaining their socially productive roles than men, as this allows them a means to reduce the possibility of discrimination and stigmatization.
- Women's concerns about self-stigmatization are strongly tied to their role as potential provider of brideprice and equity to be obtained through marriage. Several women linked their decrease in physical well-being as a threat to their good

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relationships with their parents and family, and being criticized on this front made them feel not worthy.

- Men appear to spend less time worrying about keeping up appearances, and appear to have to do less to maintain their sense of social worth than women. However, men were less likely to access ARVs than women which suggests strong concerns with the potential loss of social status associated with disclosure.
- Secrecy was a key strategy expressed by both men and women for retaining control of their social situation. Secrecy and denial are acts of refusing to give in to the stigma and hopelessness that seems to accompany HIV diagnosis in Papua.

Health Care and Stigma:

- While all health care staff (indigenous and migrant) appear caring and try and implement best practices in their clinic work, ethnicity appears to be important in how patients perceive care. When health care staff are indigenous, persons who suspect they may have HIV are more likely to go for testing, and to follow-through on testing with ARV therapies and counselling.
- Some health care workers who have received training for voluntary counselling and testing agree with overtly discriminatory statement such as that ODHA are dirty, should be shunned, and should receive a punishment. Most workers agreed with more subtly stigmatizing statements, such as ODHA having to accept limits on their behaviour or assuming that ODHA will feel ashamed of their status.
- Violations of confidentiality affect the willingness of Papuans to go for HIV testing. Many respondents said they were afraid health care workers (both indigenous and migrant) would not respect their secrets. Secrecy is the ODHA's primary concern, but confidentiality is routinely violated at health services in Papua. As one respondent noted: "Confidentiality? It doesn't work at all. In fact, it might as well not exist." In interviews with VCT staff, counsellors and office support staff readily acknowledge problems maintaining confidentiality in their own and their colleagues' clinical practice.
- Clients who fear confidentiality will be violated tend not to return to health services for treatment. Many clients receive HIV-test results, and flee home to villages in order to try and maintain their secrets, and prevent stigmatization and discrimination. ODHA are particularly suspicious of migrant health workers. As one indigenous nurse noted: "Papuans will say, 'Better I not get treatment there, because they might kill me. I don't want to be cared for under them, better just die.'" Papuans widely feel non-Papuan staff do not respect their values, and judge them on Indonesian terms. When they seek care they seek out indigenous staff at almost every opportunity.
- When ARV therapies are offered at locations run by indigenous persons, such as an indigenous-run AIDS clinic, or an indigenous-run NGO that provides therapies to patients, indigenous patients are more likely to receive support there, and to adhere

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to regimens. Women appear more likely to go to indigenous-run NGOs to receive care and treatment than to the hospital or clinic.

Key Recommendations

- Acknowledge stigmatizing practices and cultural patterns of secrecy result in very low levels of ARV uptake.
- Respond to very low rates of HIV testing and high levels of fear by training more Papuan outreach workers to spread information about counselling and therapies and how to access them.
- Develop more concrete measures to train religious leaders about the damage of stigma by religious groups.
- Develop concrete measures to train migrant health care staff about the impact of ethnicity on how patients perceive care.
- Provide respectful care and support services that can be accessed through public or NGO facilities, rather than trying to involve the family of ODHA or visit ODHA homes to oversee domestic conditions. This will minimize current fears that services do not reflect cultural norms.
- Promote ODHA care through promoting tribal solidarity. Rather than encouraging a global model of confidentiality and respect that emphasizes the individual, encourage communication about stigma from the perspective of clan survival and prosperity. Work with sustained strong identities aligned along the lines of clan and tribe.
- Acknowledge gender differences in women and men's access to testing, and in responses to HIV diagnosis and treatment. Provide more information about HIV testing that is directed specifically to women, and make it easier for women to access testing. Assess new strategies for providing support and treatment for men.
- Provide more support for the NGOs that provide excellent care, support and treatment for ODHA. Involve indigenous NGO staff who have excellent rapport with patients in training migrant health workers to develop more respectful treatment approaches.
- Increase the role of NGOs in providing support for women ODHA, and explore ways NGOs can develop more effective support for male ODHA.
- Provide more rewards for health care workers who are successful in treating ODHA in order to encourage them to remain in their positions. Promote the use of Papua-specific materials and case studies in training.
- Promote the much greater participation of Papuans in the care and support of ODHA. Acknowledge the importance of ethnicity in shaping how Papuan ODHA respond to their HIV status.

2. Ringkasan Eksekutif

Provinsi Papua memiliki jumlah kasus penularan HIV tertinggi per kapita di Indonesia dan termasuk salah satu tertinggi di Asia. Di wilayah pegunungan tengah yang terpencil, penanganan HIV sudah menjadi proyek besar diantaranya mencakup penyediaan informasi dasar ke berbagai kelompok masyarakat terisolir, penyediaan akses tes dan konseling, serta pemberian pengobatan untuk mereka yang benar-benar menjalani tes. Tingkat penularan sering diperkirakan sekitar 2% dari jumlah penduduk, namun diantara penduduk pribumi pegunungan perkiraan terbaru sekitar 7% yang positif terkena HIV. Akses ke pengobatan ARV, dukungan dan penanganan sangatlah terbatas, walau sudah ada upaya terpusat dalam dua tahun terakhir ini untuk melatih staff dan memperbaiki distribusi dan akses ke obat-obatan. Hanya 45 orang saat ini mengikuti pengobatan ARV di kabupaten Jayawijaya walaupun lebih dari 800 orang telah dites positif HIV, suatu kenaikan sebesar hanya 6%. Hanya 7 orang dari 64 orang yang positif mengidap HIV di Enarotali yang sedang menjalani pengobatan ARV, suatu kenaikan sebesar hanya 10%. Layanan yang disediakan masih apa adanya, keterbatasan pendampingan dan minimnya pelatihan. Obat-obatan yang disediakan untuk mengobati HIV mestinya gratis namun kadang tidak demikian. Penyediaan obat-obatan tidak terus menerus. Tingkat pemberian informasi yang salah tetap tinggi di wilayah pedalaman/pegunungan. Banyak kelompok masyarakat telah terinfeksi HIV pada tingkatan yang tinggi namun kesadaran tentang HIV tetap rendah. Potensi terjadinya kesalahpahaman, interpretasi yang keliru, dan praktek-praktek stigma di wilayah pegunungan sangat tinggi. Dalam kondisi seperti ini— tingkat penularan/infeksi yang tinggi serta tidak adanya pengetahuan tentang terapi – maka praktek-praktek stigma menjadi kurang dipahami namun berakibat sangat merugikan bagi para individu dan kelompok-kelompok masyarakat.

Tujuan dari penelitian ini adalah untuk menggambarkan pengalaman-pengalaman yang dihadapi oleh para ODHA di wilayah pegunungan di Papua (istilah ODHA dipakai dalam penelitian ini untuk penduduk asli Papua yang mengidap HIV/AIDS), terutama di wilayah kabupaten Jayawijaya. Kami memberi penekanan khusus pada hubungan antara gender, layanan kesehatan, dan bagaimana kondisi-kondisi saat ini-- ekonomi dan politik—dapat mempengaruhi berbagai pengalaman stigma. Kami membedakan antara **stigma** dan **diskriminasi**. Istilah stigma didefinisikan sebagai perbedaan-perbedaan yang nilainya berkurang yang dari sisi pandang social mendiskreditkan orang tertentu, dan dikaitkan dengan berbagai stereotype negative. Diskriminasi sendiri didefinisikan sebagai tindakan-tindakan tertentu yang didasarkan oleh berbagai stereotipe negatif tadi, aksi-aksi yang dimaksudkan untuk mendiskredit sekelompok orang yang kurang beruntung. UNAIDS mendorong pemahaman yang lebih besar tentang bagaimana stigma dan diskriminasi mempengaruhi upaya-upaya/respons terhadap HIV. Dalam penelitian ini kami memberi penekanan khusus pada hubungan-hubungan antara gender dan stigma, dan juga tentang bagaimana kondisi saat ini – ekonomi, politik, dan layanan kesehatan mempengaruhi pengalaman-pengalaman stigma. Pertanyaan-pertanyaan penelitian yang diajukan proyek ini adalah:

- a. Apa saja pengalaman-pengalaman stigma dan diskriminasi oleh para penduduk asli Papua yang positif HIV yang tinggal di pedalaman/pegunungan Papua?
- b. Bagaimana perbedaan-perbedaan pengalaman yang dialami dilihat dari sisi gender?
- c. Bagaimana kondisi saat ini, khususnya standard-standar layanan kesehatan,

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mempengaruhi pengalaman stigma dan diskriminasi?

Belum ada penelitian tentang pengalaman-pengalaman tentang orang yang hidup dengan HIV/AIDS di kabupaten pegunungan, dan juga masih sedikit sekali untuk Papua secara menyeluruh. Laporan ini merangkum hasil-hasil penelitian kualitatif orisinil yang dilaksanakan tahun 2009 di Papua, Indonesia. Wawancara mendalam dan observasi dilaksanakan antara bulan Mei dan November di dua lokasi pedalaman; kota Wamena di kabupaten Jayawijaya dan kota Enarotali di kabupaten Paniai. Sebanyak 28 ODHA diwawancarai untuk proyek ini. Sebanyak 28 ODHA diwawancarai untuk proyek ini. Suku Dani, Yali, Lani, dan Mee merupakan kelompok-kelompok utama yang dibahas disini. Materi-materi dari suku Mee digunakan sebagai materi klarifikasi dan pembenaran. Sebelas staf kesehatan terlibat dalam pemberian konseling, testing dan pengobatan (treatment) di Wamena juga diwawancarai. Observasi partisipan dilakukan selama penelitian. Tujuannya adalah untuk menggambarkan pengalaman-pengalaman dan kondisi dari ODHA yang bisa digeneralisasi untuk mewakili pengalaman-pengalaman dan kebutuhan-kebutuhan orang-orang asli Papua yang positif HIV di wilayah pegunungan/pedalaman.

Hasil Penelitian

Orang-orang asli Papua yang positif HIV dan Stigma:

- Usia dari 28 ODHA yang diwawancarai dalam studi ini berkisar dari 15-52 dengan rata-rata usia 25 tahun. Lima belas dari 28 responden adalah perempuan dan 13 orang laki-laki. Kebanyakan para responden memiliki tingkat penghasilan/pendapatan yang rendah atau menengah, namun ada beberapa dari mereka yang memiliki pekerjaan tetap dengan gaji tetap. Tingkat pendidikan mereka semuanya rendah, dan perempuan berpendidikan kurang dari sekolah menengah. Para laki-laki berpendidikan agak sedikit lebih tinggi. Pola ini menggambarkan norma-norma yang berlaku di wilayah pegunungan Papua.
- Semua responden positif HIV dan sudah menjalani tes guna mengkonfirmasi status mereka. Dari semuanya cuma 3 orang saja yang saat ini menjalani terapi ARV yang disediakan oleh 5 lokasi layanan kesehatan yang berbeda. Tiga orang yang saat ini tidak menjalani terapi menjalani pengobatan tradisional yaitu ramu-ramuan yang diambil dari hutan setempat.
- Penelitian ini mengungkapkan adanya ketakutan-ketakutan yang luar biasa tentang stigma dari para responden, dan berbagai upaya ekstrim yang dilakukan para responden untuk mencoba dan melindungi diri mereka dari stigma. Banyak responden menyebutkan cerita-cerita yang sudah diketahui tentang orang-orang yang 'dihukum' hingga hampir mati, atau dihina oleh masyarakat, yang mereka pakai sebagai alasan untuk melindungi diri mereka.
- Seluruh responden menceritakan paling kurang adanya pengalaman tentang stigma. Beberapa responden menceritakan pengalaman-pengalaman luar biasa tentang stigma dan diskriminasi sehingga mereka diperlakukan dengan sangat tak adil dan tak bisa hidup secara normal. Ada beberapa responden yang menceritakan stigma yang mereka alami dalam tingkatan yang sedang-sedang saja yang menyebabkan modifikasi perilaku yang cukup besar namun tak merubah sama sekali perilaku sosial mereka. Seorang responden menyatakan bangga dan kemauan keras dalam menghadapi diskriminasi.
- Hampir semua responden memilih untuk paling tidak memberitahu kepada satu orang lain tentang status HIV mereka. Baik laki-laki maupun perempuan secara konsisten tidak mau memberitahu para anggota terdekat keluarga mereka – biasanya isteri, suami, orang tua,

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atau saudara perempuan dan saudara laki-laki. Hanya dua responden mengatakan mereka secara sukarela memberitahu para kerabat keluarga mereka, dan tak ada yang terus terang memberitahu status mereka ke teman-teman mereka. Alasan terbesar untuk tidak memberitahu status mereka adalah takut akan stigmatisasi.

- Para responden menceritakan praktek-praktek stigma datang dari beragam sumber, yang mempertanda bahwa akar stigma berasal dari praktek-praktek budaya yang dekat yang tak jauh berbeda dengan yang terjadi di kondisi-kondisi ekonomi makro atau politik yang lebih besar. Secara khusus, para responden dengan jelas menyebutkan stigma berasal dari:
 - pengungkapan status mereka oleh orang lain; pengungkapan status mereka oleh orang lain yang memiliki kekuasaan seperti pemimpin gereja atau petugas kesehatan;
 - kesalahan dalam penyediaan layanan kesehatan termasuk pelanggaran atas kerahasiaan; kurangnya akses ke ARV atau pelanggaran akses; diskriminasi di tingkat kerabat dan masyarakat; pikiran-pikiran budaya dan praktek-praktek menyangkut sakit yang serius; nilai-nilai budaya seputar kematian dan ajal; nilai-nilai budaya menyangkut pengucilan; kondisi-kondisi politik yang menyebabkan rasisme; ketidakadaan atau tidak cukupnya layanan kesehatan; penundaan dalam penyediaan berbagai layanan dasar.
- Pengungkapan status HIV seseorang yang dilakukan secara meluas membawa dampak negatif yang serius baik terhadap perempuan maupun laki-laki di pedalaman/pegunungan Papua. Pengungkapan yang terjadi oleh orang-orang yang memiliki kekuasaan tampaknya membawa dampak amat merugikan/merusak bagi seorang ODHA. Stigmatisasi menjadi sangat mencekam bilamana seorang pemimpin gereja mengungkapkan/mengumumkan status mereka ke masyarakat. Responden-responden lainnya menceritakan stigmatisasi ekstrim yang terjadi ketika seseorang pekerja kesehatan mengungkapkan status mereka ke masyarakat luas.
- Adanya suatu zona antara yakni pengungkapan separoh yang menunjukkan pentingnya dukungan keluarga dan mempertahankan kerahasiaan. Para peneliti mengumpulkan sejumlah kasus dimana ODHA amat dicurigai mempunyai HIV, dan dimana ada sejumlah orang dalam masyarakat atau keluarga besar/kerabat menuduh ODHA positif mengidap HIV. Namun tidak satupun orang-orang yang memiliki pengaruh di masyarakat yang membela responden, sedangkan para keluarga dan pasangan hidup menunjukkan sikap menolong. Dalam kasus-kasus ini keluarga inti dan kerabat dekat memainkan peran kritis dalam melindungi responden dari diskriminasi yang memperparah keadaan.
- Nilai-nilai budaya mempengaruhi respons terhadap stigma hingga ke tingkatan tertentu. Diantara masyarakat pegunungan, penarikan diri secara sosial merupakan suatu respons budaya yang disetujui terhadap suatu penyakit serius yang dianggap menular. Seseorang kadang mengucilkan diri dan hidup sendiri di dalam hutan. Sebagai akibatnya, penarikan diri dan isolasi merupakan sesuatu yang sah dan biasa sebagai respons terhadap diagnosis HIV. ODHA tak mengupayakan terapi ARV.
- Kerahasiaan merupakan suatu strategi budaya utama yang dinyatakan oleh laki-laki maupun perempuan untuk mempertahankan kontrol situasi sosial mereka. Kerahasiaan dan penyangkalan dilihat sebagai strategi-strategi sah untuk menolak datangnya stigma dan keputusan yang tampaknya mendampingi diagnosis HIV di Papua. Para petugas kesehatan menjelaskan pola budaya dominan yakni “kembali ke kampung dan mati.” Beberapa petugas kesehatan memperkirakan 75% dari orang-orang yang awalnya dihubungi

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merespon dengan cara ini, dan 90% dari mereka yang dites positif juga melarikan diri tanpa meminta layanan. Ini merupakan suatu gap besar dalam penyediaan layanan ke masyarakat.

Gender dan Stigma:

- Studi ini menunjukkan sejumlah perbedaan besar menyangkut bagaimana laki-laki dan perempuan merespon terhadap tes HIV dan terapi ARV.
- Laki-laki cenderung menjalani tes HIV dibanding perempuan.
- Perempuan lebih cenderung menjalani terapi ARV dibanding laki-laki.
- Pengalaman-pengalaman stigma pada kasarnya sama untuk laki maupun perempuan. Tema-tema dominan bagi kedua gender adalah mereka merasa adanya stigma bila mereka tidak mampu menjadi manusia yang berguna sebagai manusia yakni dengan memenuhi peran-peran sosial mereka dalam keluarga, yang berkenaan dengan tanggungjawab, anak-anak, tanggungjawab perkawinan, pekerjaan dan kontribusi keuangan.
- Ada berbagai perbedaan dalam stigma internal (nilai-nilai negatif yang dibuat supaya orang yang ditarget percaya bahwa nilai-nilai itu benar tentang dirinya) antara laki-laki dan perempuan. Perempuan lebih mencernai stigma dibanding laki-laki. Para perempuan lebih sangat merasa tak dihargai atau dibutuhkan. Laki-laki merasa status mereka sebagai kesalahan mereka dan mereka merasa malu tentang diri mereka sendiri namun mereka tidak terlalu merasa hilang harga diri dibanding perempuan.
- Perempuan kurang begitu mampu mengurangi efek negatif dari pengungkapan status mereka. Ketika perempuan menjadi target dari stigma dan diskriminasi, mereka menjadi target yang luar biasa. Sehingga, perempuan menunjukkan suatu kekhawatiran yang lebih besar dalam mempertahankan peran-peran sosial mereka yang produktif dibanding laki-laki. Menjadi produktif secara sosial memudahkan mereka untuk mengurangi kemungkinan diskriminasi dan stigmatisasi.
- Kekhawatiran perempuan tentang stigmatisasi diri sendiri sangat erat dengan peran-peran mereka sebagai potensi penyedia mas kawin dan barang-barang lain melalui perkawinan. Beberapa perempuan menghubungkan menurunnya keadaan tubuh mereka sebagai ancaman terhadap hubungan baik mereka dengan orang tua dan keluarga, dan bila dikritik tentang hal ini akan membuat mereka merasa tidak berharga.
- Laki-laki tampaknya mengalami sedikit kesulitan dalam menyembunyikan kondisi mereka dan tidak banyak ambil pusing tentang penampilan mereka. Namun, laki-laki kurang mendapat akses ke ARV dibanding perempuan yang menunjukkan bahwa laki-laki amat khawatir tentang potensi hilangnya status sosial yang muncul lewat pengungkapan status.

Layanan kesehatan dan stigma:

- Orang-orang asli Papua amat membutuhkan tes HIV, konseling dan pengobatan dibanding orang-orang pendatang yang hidup di pedalaman karena pengidap HIV lebih banyak orang asli Papua dibanding orang pendatang/migran. Namun, menurut banyak responden, orang-orang asli Papua cenderung lebih menyukai layanan kesehatan yang diberikan oleh para pekerja kesehatan yang berasal dari orang asli Papua dibanding layanan kesehatan dari pekerja kesehatan yang berasal dari petugas kesehatan luar Papua/pendatang. Meski semua petugas kesehatan (asli Papua dan pendatang) tampaknya menunjukkan perhatian dan berupaya bekerja dengan sebaik-baiknya, etnisitas tampaknya menjasi hal penting yang

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mempengaruhi apakah pasien merasa mereka di-stigma atau tidak. Bila para petugas kesehatan adalah orang-orang asli Papua maka orang-orang yang akan menjalani tes (merasa memiliki HIV) akan benar-benar mengikuti tes dan kemudian dan melanjutkannya dengan terapi ARV dan konseling.

- Sejumlah petugas kesehatan yang telah memperoleh pelatihan konseling dan tes sukarela (VCT) setuju dengan adanya pernyataan berlebihan yang sifatnya diskriminatif seperti: ODHA itu kotor, mesti ditolak dan mesti dihukum. Kebanyakan petugas setuju dengan pernyataan tentang stigma yang lebih halus seperti: ODHA mesti menerima pembatasan atas perilaku mereka atau beranggapan bahwa ODHA akan merasaa malu dengan status mereka.
- Pelanggaran atas kerahasiaan mempengaruhi keinginan klien untuk menjalani tes HIV. Banyak responden mengatakan mereka takut para petugas kesehatan (asli Papua dan pendatang) tidak akan menjaga rahasia mereka. Kerahasiaan terus dilanggar di pusat-pusat pelayanan kesehatan di Papua. Seperti diungkap seseorang responden: “Kerahasiaan? Sama sekali tidak ada. Malahan, bisa saja tidak ada sama sekali.” Dalam berbagai wawancara dengan staf VCT, konselor dan staf kantor sama-sama mengakui persoalan dalam menjaga kerahasiaan baik pada diri mereka sendiri juga dengan praktek klinis rekan-rekan kerja mereka. Para pasien takut bila ada seorang petugas kesehatan yang datang mengunjungi rumah seorang ODHA untuk mengawasi makanan dan layanan dalam keluarga.
- Para klien yang takut kerahasiaannya terungkap cenderung tidak kembali lagi ke layanan kesehatan untuk mendapatkan pengobatan. Banyak klien yang menerima hasil tes HIV, dan melarikan diri ke kampung-kampung dalam upaya menyembunyikan rahasia mereka. ODHA secara khusus curiga terhadap petugas kesehatan pendatang. Seperti salah satu perawat asli Papua katakan: “Orang-orang Papua akan berkata seperti ini, ‘Lebih baik tidak mendapat perawatan disini karena mereka akan bunuh saya, saya tidak mau dirawat mereka, lebih baik mati saja.’” Orang-orang Papua secara meluas merasa bahwa staf kesehatan pendatang tidak menghormati nilai-nilai mereka (orang Papua), dan menilai mereka menurut aturan-aturan Indonesia. Mereka akan berupaya mencari petugas kesehatan orang asli Papua di setiap kesempatan.
- Ketika terapi ARV diberikan di lokasi-lokasi yang diselenggarakan oleh orang asli Papua, seperti klinik AIDS atau LSM yang dijalankan oleh orang asli Papua yang menyediakan terapi bagi pasien, maka pasien orang asli Papua akan lebih mudah mendapat dukungan disitu, dan menuruti aturan-aturan yang ditetapkan. Perempuan tampaknya lebih mungkin pergi untuk mendapatkan terapi di LSM-LSM yang dijalankan oleh orang Papua guna mendapatkan layanan dan pengobatan dibanding ke rumah sakit atau klinik.

Rekomendasi-rekomendasi utama

- Merespon rendahnya tingkat tes HIV dan tingginya tingkat ketakutan dengan melatih lebih banyak orang asli Papua sebagai tenaga outreach guna menyebarkan informasi tentang konseling dan terapi serta bagaimana mendapat akses ke konseling dan informasi.
- Mengembangkan tindakan-tindakan nyata guna memberi pelatihan penyadaran bagi para tokoh agama tentang dampak buruk dari stigma oleh kelompok-kelompok agama.

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- Mengembangkan tindakan-tindakan nyata guna memberi pelatihan penyadaran bagi para petugas kesehatan pendatang tentang bagaimana praktek-praktek layanan kesehatan yang berpihak sebelah (bias) bisa meningkatkan ketakutan dan stigma.
- Mengakui pentingnya isu etnis dalam membentuk bagaimana ODHA Papua merespon terhadap status HIV mereka.
- Memberi layanan dengan rasa hormat serta dukungan layanan yang bisa diperoleh lewat berbagai fasilitas umum dan yang disediakan LSM, dari pada melibatkan keluarga ODHA atau mengunjungi rumah-rumah ODHA untuk melihat kondisi keluarga. Ini akan mengurangi ketakutan saat ini bahwa layanan-layanan saat ini terlalu mengganggu.
- Mempromosikan layanan ODHA lewat promosi solidaritas kesukuan. Dari pada mendorong model kerahasiaan global dan rasa hormat yang menekankan perorangan, dorong komunikasi tentang stigma dari perspektif kelangsungan hidup suku dan kesejahteraan. Mulai dengan identitas-identitas kuat apa yang dipunyai klan dan suku.
- Akui perbedaan-perbedaan gender pada laki-laki dan perempuan menyangkut akses ke tes, serta respon terhadap diagnosa HIV dan pengobatannya. Berikan informasi lebih banyak tentang tes HIV yang diarahkan khususnya bagi perempuan dan permudah akses tes bagi perempuan. Coba berbagai strategi baru guna menyediakan dukungan dan pengobatan bagi laki-laki.
- Berikan lebih banyak dukungan bagi LSM-LSM yang memberi layanan yang prima, dukungan dan pengobatan bagi para ODHA. Libatkan staf LSM pribumi Papua yang memiliki sejarah penanganan pasien yang baik dalam pelatihan petugas kesehatan bagi petugas kesehatan pendatang/ non Papua guna mengembangkan pendekatan-pendekatan pengobatan yang lebih didasarkan pada rasa hormat.
- Tingkatkan peran LSM-LSM dalam penyediaan dukungan bagi ODHA perempuan, dan telusuri cara-cara LSM agar bisa mengembangkan dukungan yang lebih efektif bagi ODHA laki-laki.
- Sediakan ganjaran (rewards) bagi para petugas kesehatan yang sukses dalam mengobati ODHA agar mendorong mereka untuk tetap berada dalam posisi mereka. Promosikan penggunaan materi-materi yang spesifik Papua serta studi-studi kasus dalam pelatihan.
- Promosikan partisipasi yang lebih besar dari orang-orang asli Papua dalam layanan dan pengobatan ODHA.

3. Introduction

The province of Papua has the highest incidence of HIV infection per capita in Indonesia, and among the highest in Asia. In the remote central highlands of the province, managing HIV has become a huge project that involves getting basic information out to isolated communities, providing access to testing and counselling, and offering medications to manage HIV and AIDS to those few who do get tested.

Rates of infection have been often estimated at 2 to 3 per cent of the general population in the province of Papua, but among indigenous highland populations, new estimates suggest around 7% are HIV-positive (Rees et al. 2007). Transmission in the highlands appears to occur primarily through heterosexual encounters. In the highlands, reports of HIV rates have consistently been low because mechanisms for reporting have been inadequate. In the former Jayawijaya district (population 250,000) in the central highlands, for example, if we estimate a 7% infection rate, there may be 17,000 persons infected, far more than the 800 who have tested positive as of May 2010.

Although migrants make up a significant percentage of the Papuan population, it has become clear that more indigenous Papuans contract HIV than do migrants. A 2007 report shows that HIV prevalence among Papuans is almost twice as high as among non-indigenous residents (Irmanigrum et al. 2007:49). Disproportionate infection rates are particularly obvious in the highlands region, where a 2009 testing drive that targeted both indigenous Papuans and Indonesian migrants found that 100% of those who tested positive were indigenous Papuans. As the test drive coordinator noted: “for me it was as though a red light went on. This is a crisis for the Papuan people.”

In these communities, access to ARV treatment, support and care is extremely limited. The efforts since the early 2000s in the rest of Indonesia to make ARVs and testing more widely available have not been carried out in most of the highlands (Spiritia Foundation 2006; Green 2010). Services remain bedevilled by corruption, lack of follow-through, and poor training. Money sent from external agencies does not appear to make its way down to local communities. The drugs available to treat HIV are supposed to be free but often are not. Drugs for opportunistic infections such as TB are not free. Drug supply is erratic. ARVs have only reliably been available at the province’s flagship site on the coast since 2007, and in some highlands districts only since 2008 (with the exception of the region around Timika). Even though the drugs are available, the uptake is extremely low. In 2010, only between six and ten per cent of people who test HIV-positive go on to begin a course of ARVs. Over 90%

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of those tested flee without taking any drugs at all. This number is shockingly low. This report suggests that stigma is a key factor in this low uptake.¹

Unlike in the rest of Indonesia, ODHA in highlands Papua do not necessarily have a clear picture of HIV and its treatment.² Levels of disinformation remain high in many parts of the highlands, such that many communities are already experiencing high levels of HIV infection, but awareness about HIV remains low. In situations like this, the potential for misunderstandings and consequent discrimination is rife. However, there has been no research on experiences of living with AIDS in the highland district, and very little within Papua as a whole.

The goal of this research was to describe the experiences of indigenous persons living with HIV and AIDS in highlands Papua (the acronym ODHA is used to refer to indigenous persons living with HIV/AIDS in this report), primarily in the Jayawijaya district. We give particular emphasis to the links between gender, health care, and how current conditions -- economic and political -- might affect experiences of stigma. This project questions:

- a. What are the experiences of stigma and discrimination for HIV-positive indigenous persons in highlands Papua?
- b. How does this experience differ by gender?
- c. In what ways do current conditions, especially health care, affect the experiences of stigma and discrimination?

The term stigma is central to this project. We distinguish between **stigma** and **discrimination**. The term stigma can be defined as devalued differences that are seen as socially discrediting, and that are linked to negative stereotypes. By discrimination, we mean specific acts that build on these negative stereotypes, actions are meant to discredit and disadvantage people (Maman et al. 2009:2272). In practice, the stigmatized individual is *perceived* as a challenge to the moral order (stigmatization), and hence is someone who must be *put down*, or isolated (discrimination). Parker and Aggleton (2003) have emphasized how stigma can occur at multiple levels. They identify 4 main levels: self; society; institutions; and structure, as described in Table 1.

¹ The link between high levels of stigma and low uptake has been reported in other areas of the world. See UNAIDS 2007

² Compare with Green (2010) and Boellstorff (2009)

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Table 1: Four Levels of Stigmatization

<u>Four Levels of Stigmatization</u>
<u>Self</u> : self-generated internal mechanisms, which we term self-stigmatization
<u>Society</u> : gossip, abuse and ostracism at the level of culture and community
<u>Institutions</u> : preferential or discriminatory treatment in institutions
<u>Structure</u> : Wider institutions such as poverty, racism, and colonialism that consistently discriminate against a particular group.

This project also looks at differences in stigma along the lines of gender. Stigma feeds on existing inequalities and follows along the “fault lines” of society (Eves and Butt 2008). Thus, women are already understood as stigmatized when they are part of a culture or community where they have lower social status and less access to political and economic resources than men (Reidpath et al. 2005). The fears aroused by the AIDS epidemic can intensify gender politics, making existing discrimination worse. In epidemics, women are often blamed as the vector of disease and disaster, and singled out as “dirty, diseased and undeserving” (Lawless et al. 1996).

Last, this project explores the role of health care in stigmatizing processes. Within Indonesia, studies are reporting stigmatizing practices by health care workers in many parts of Indonesia. Workers often violate confidentiality of the patient (Suherman 2009, Sumintardja 2009, Haruddin 2009). The patterns appear far more problematic in Papua. Most of the province’s health care institutions are still run by Indonesian migrants to the province. Patients report being discriminated against by migrant health workers. Health care services within the region also reflect an unstable economy, inadequate infrastructures, and racial inequities that tend to privilege wealthier migrant Indonesians over indigenous populations. Health care is viewed by most Papuans from within this economic and political context. Papuans often view efforts to improve health conditions as inadequate, and their critiques extend to HIV prevention and treatment as well.

The living conditions of culture, gender, and health care affect how ODHA view the issues of stigma and HIV/AIDS. The results from this study privilege the voices of ODHA interviewed for this project. The intention is to make recommendations about possible strategies that build on respect for the experiences of ODHA, and that can be applied to the highlands Papuan region as a whole.³

³ The highlands region includes the following ten kabupaten: Paniai, Yalimo, Nduga, Puncak Jaya, Mamberamo Tengah, Pegunungan Bintang, Yahukimo, Tolikara, Lanijaya, and Jayawijaya.

4. Methods

This report summarizes the results of original qualitative research conducted in 2009 in Papua, Indonesia. Experienced Papuan researchers from the Universitas Cenderawasih-Abepura interviewed 28 ODHA, using qualitative research methods.

In-depth interviews and observations were conducted in two highland locations; the town of Wamena, in Jayawijaya district, and the town of Enarotali, in Paniai district. Four different tribal groups are represented in this research, the Lani, the Dani, the Yali, and the Mee. These locations are representative of general trends in the highlands district.

Fifteen of the respondents were adult women, the other 13 were men. All are indigenous. Each researcher interviewed persons of their own gender whenever possible. Researchers used an ethics protocol approved by the University of Victoria. Researchers used a standardized interview protocol for all interviews. All of the ODHA discussed in this report have been given pseudonyms. If an ODHA wanted to be part of the research project, they contacted the researchers directly. Care was taken at every step of the way not to coerce respondents in any way. Having indigenous researchers made a positive difference in how potential respondents viewed the interview process.

Eleven health care staff involved in the provision of counselling, testing and treatment in Wamena were also interviewed. These interviews focused on the ideals, values and practices among health care staff. These results allows analysis to focus on the possible stigmatizing effects of health care providers, rather than assume trained staff would only have a positive benefit on the lives of HIV-positive persons.

It is important to acknowledge what is *not* included in these results. These results do not reflect the experiences of all HIV-positive persons in the highlands district because the vast majority of HIV-positive people are afraid to get tested, take ARV therapies, or disclose their status. Everyone we interviewed had tested positive for HIV, and all but three were currently on ARVs. In other words, the people we describe in the pages that follow are among the best served in the region.

5. Stigma and HIV status: Disclosure is Everything

Results from all 13 men and 15 women interviewed show an overwhelming fear of stigmatization. This fear traversed all age groups, all income levels, and both genders. Our respondents were aged from 15 to 52, with an average age of 25. Most respondents had low or medium levels of income, but several had secure positions with a fixed salary. Education levels were overall low, with most women receiving less than a high school education. Men were slightly better educated.

Across this diverse range of people, respondents described experiencing stigma from many different sources. These include:

- involuntary disclosure of their status by others
- voluntary disclosure of their status by others
- disclosure by a person in a position of power such as a church leader or a health care worker
- disclosure by spouse or parent
- errors in the provision of health care
- lack of access to ARVs or non-confidential access
- lack of knowledge about HIV, transmission, and ARVs
- discrimination at the level of extended kin and community
- cultural ideas and practices surrounding serious illness
- cultural values around death and dying
- cultural values of ostracism
- political conditions leading to racism
- absent or inadequate health care
- delays in the provision of basic services
- self-stigmatization

This compilation is wide-ranging. It reminds us that the roots of stigma lie in close cultural practices as much as in larger macro-economic or political conditions. It is misleading to assume that stigma exists only in the obvious domain of overt public discrimination, such as when someone refuses to share food with an ODHA. Stigma can be subtle and insidious. The ODHA we interviewed appear aware of the multiple avenues of stigma, and as a result they try to protect themselves from being stigmatized in multiple ways.

Controlling Disclosure Controls Stigma

The most important strategy ODHA use to control stigma is to try and control who they disclose their status to. The act of disclosure is a critical event in the lives of ODHA. Almost all of the respondents had chosen to tell at least one person about their status. Only one

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person did not tell anyone. However, no respondent voluntarily went public with their status. Both men and women consistently contained their disclosure to close family members – usually husband or wife, parents, or sister or brother. Only two respondents said they had voluntarily told extended family members, and no one had revealed their status to their friends.

Both men and women said they received support from their nuclear families, but not all families welcomed ODHA kin. One of our respondents described how her father yelled at her, beat her, and banished her from his house because her “wanton ways” resulted in her ODHA status. In contrast, another woman’s husband unconditionally accepted her HIV status even though he himself was HIV negative and it was unclear how she had become infected. By and large, in highlands Papua close family members support their ODHA relatives. One man was completely shunned by his church, his clan and his community, but his family continued to support him. He says:

There are only three of us here: me, my father and another relative of my father’s. They say that if I die, they will die with me too. So we live together, we eat together, we sit together, and we tell stories together. It is they who bathe me, who take me to the bathroom, and who help me with everything that I need.

Both men and women did not expect support from extended family or friends. In fact, active stigmatization happens often among distant kin and neighbours, and is the form of stigmatization 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.

On the other hand, disclosure that is tightly controlled allows an ODHA to retain some control over how others perceive them. For example, Jebo, a young woman, says:

I’m shy, I’m afraid if anyone knows my status. I heard on the radio that if you have HIV then you will die. So I don’t want to tell anyone, I’m afraid. So I pretty much stay home, if anyone sees me they will suspect I have HIV. Better for me to sit in the *honai*, looking out, than go keep my husband company at his work... My husband knows I am sick, but maybe he only thinks I have a regular sickness.... So when I am sick he forbids me to help him clear rocks from the river.”

Jebo, like many other respondents, had an overall low understanding of HIV, despite the regular encounters with health personnel. The lack of knowledge encourages self-stigmatization. ODHA often do not know facts about transmission or what ARV drugs can do

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for them. Self-stigmatization in turn leads to a lower quality of life, and to a life lived without respect or dignity.

Many of our respondents described a situation of partial disclosure. Often, the ODHA was strongly suspected of having HIV. But there were no powerful public figures stating this, and their families were supportive. In these cases, the nuclear family and close kin played a critical role in shielding the respondent from debilitating discrimination, and the respondent was able to pretend to the wider community. This helped manage gossip, one of the most important sources of stigmatization. A large number of respondents made statements like this:

If people have opinions about me and my status they haven't yet said anything to my face. But what they say when I am not there I do not know. Maybe they talk about me and maybe they don't.

When I first got sick, I stayed in my house, but I thought people were talking, "what's Meon sick with?" Then I would say "I've taken some medicine" and they would answer with "Meon before your body was skinny and now your body is good again." I feel certain there are among them several who already know I am sick.

About three or four times a month I have to stop work or school because I am sick. Usually, my teacher or friends will ask me, "why are you so wan and sick?" and I have to lie "I worked hard in the market from morning to night, I didn't get enough sleep, so I'm sick."

Extreme Stigmatization and Disclosure by Persons in Positions of Power

Disclosure that occurs by people in positions of power or authority appears to be particularly damaging for an ODHA's ability to live with respect and dignity. The discrimination and self-stigmatization are overwhelming when made public by prominent people. In one case, a church leader told the community of a person's status with devastating consequences:

Case Study

Yohlua:⁴ "I am horribly tormented in my soul"

Yohlua is a young man who contracted HIV while away at post-secondary education outside of Papua. When he returned home, a church leader had told everyone in his community of his status. Yohlua said: "Everyone in 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

⁴ All names and locations have been changed in this report to protect anonymity of respondents.

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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.

A woman experienced similar levels of ostracism when a health care worker revealed her status to her husband and to the wider community, as the case of Tina shows:

Case Study

Tina: “Hey kids, don’t play near her”

Tina’s is a woman in her mid-twenties whose husband abandoned her one year ago when he learned of her HIV-positive status through the health care worker who took her blood test. According to Tina, “the first to be told was Dr. Agen and then the sister from the non-profit organization, then mantri Hepudo, and then others knew too. So from mouth to mouth the information spread and then everybody knew.”

Tina has had to live with her parents, but as their house is very small she sleeps in the living room. While her parents care for her they are also impatient with her because she requires special and expensive foods. She has so many sores in her mouth she cannot chew sweet potatoes, the staple food. Tina is clearly ill, and has a panoply of medications in the living room. Her status is well known in the wider community. The worst are the neighbours, says Tina. She will sit outside and the neighbours will come out of their house and stare at her. They will then shoo the children away, “‘hey kids, don’t play near her’, they say, or ‘why are you just sitting there?’ so they don’t play in front of my house, it really hurts my feelings.” Tina says the health worker who took her blood test was from the same clan as her. He helped her choose her foods and gave advice. “But 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 just sitting here the health worker walks by, he just ignores me. He looked after me at the clinic, but now he just gives me the shifty eye.”

Two other respondents said their health care worker told others about their status. This appears to be a significant problem. As one ODHA noted,

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Indeed, I tried to keep it a secret, but the mantri told everyone in the community.

In sum, disclosure is far and away the most important issue affecting experiences of stigma for ODHA in highlands Papua. Fear of large amounts of discrimination from extended kin and community appear well-justified. ODHA also fear discrimination when persons of influence such as health care workers or religious leaders tell the wider community. Remaining embedded in social networks is a primary concern. Researcher Andreas Goo argues in highlands Papua that close family is the safest place to confide status. His research suggests family members will offer empathy, provide a place to sleep and live, share clothes, dishes and bathing facilities, and pray together. Family can also protect the ODHA from overt stigmatization. When the family feels empathy and accepts the ODHA's status, such support appears to be the norm. However, ODHA cannot automatically expect family support.

6. Stigma and Culture

In Papua, cultural ideas about stigma are centred around three major themes: illness; the body; and social belonging. These values are intertwined, and affect how ODHA and the wider community respond to HIV and to AIDS.

Cultural Ideas about Illness

Fear of disclosure is rooted in cultural responses to epidemic diseases. All cultural groups we interviewed agree that AIDS should be treated and understood as similar to other epidemic diseases. For serious illness, in the past complete withdrawal was the norm. 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 example, one Lani respondent 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.

People talk about AIDS primarily within existing patterns of responses to dangerous sickness. Each highlands tribe has specific explanations and understandings of epidemic illness, and each explains responses in cultural terms.

Researcher Ibrahim Peyon gives the example of how the Yali tribe view AIDS. Among the Yali, 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, 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, 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."

AIDS is often described in terms that reinforce cultural ideas about illness, the body and social exclusion. One woman was heavily stigmatized by her husband:

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AIDS for us is like the incest taboo. So wherever I go my husband says *watlasin*, or that I am 'already dead.' What is this *wataslin*? Am I the enemy or something? Did I do something wrong?

She goes on to describe how her own family cared for her but her husband's did not, because he was now in a position to ignore older tribal hierarchies:

My brother took me to the health center, cooked pig for me, chicken, good food. But what is the problem on my husband's side? I get nothing from him or his family. I am the child of a war leader. In the past, his family was below us. But now we have the government and the church and so now they think they are great, right?

This example shows that clan affiliations can affect how a person responds to requests for help from an ODHA. Spouses and in-laws may be quicker to discriminate against an ODHA than an ODHA's sibling or parent.

Cultural Ideas about the Body

AIDS is also explained in terms of cultural ideas about the body and illness. Highland tribes understand the body in terms which often differ from biomedical explanations. These cultural explanations can affect how people understand HIV. The following example shows how explanations of contagion may not fit with the models given by health workers:

An older brother explains his younger sister's HIV, "she is sick like this because since the age of thirteen, she sleeps with men, but Yoya's womb was unformed, still young, and so male sperm entered her womb but it plugged up her womb and as a result it won't open up, and the sperm stayed in there a long time and gave her cancer." "I got checked at the clinic, the nurse said I had cancer," she said. Her brother interjected, "she is short of blood because she doesn't want to eat. She wants to eat but because the male sperm is plugged up inside of her, food won't stay in her properly."

This explanation of HIV and how it was transmitted shows how cultural explanations can be the source of stigma. Highlands health care staff need to be aware of the range of explanations that can exist to explain disease. These explanations can include: blaming angry ancestors for wreaking havoc on the living, negative social relations, and individuals with the power of witchcraft or sorcery.

One prominent explanation in the highlands is that women are the vector for disease. For example, one man associated feeling dirty and being HIV-positive because of contagion through having sex with a woman.

I feel "dirty" because this disease entered me. I got this disease because it came into me through the dirty place where I had sex with a prostitute and I believe she was

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dirty too. Then the doctor told me that I have AIDS so inside my body the disease is bearing fruit. So, my body, it feels dirty.

Woman as a source of contagion was strongly reflected in many answers, and across all tribal groups. Women's bodies, in particular their reproductive organs, are widely understood as having potentially polluting or poisoning qualities. While some women pinpointed their husbands as the source of their infection, the community is much more likely to blame the woman than her husband. As a result, highland peoples often blame the transmission of HIV on sex workers or street sex workers, rather than on the men who use the services of these women.

Cultural ideas about illness, the body, and contagion strongly affect how highland peoples respond to ODHA. Biomedical knowledge appears to be less important to understanding than long-standing ideas about infection, contagion, and ostracism. Health care workers need to be trained to understand the multiple ways cultural values can discriminate against ODHA .

Culture as Protective

At the same time that culture can promote ostracism, researcher Andreas Goo argues that cultural values about family and clan support can protect the ODHA, helping keep suspicions and potential social isolation if not at bay, at least silenced. The following example describes how a particularly belligerent father protects his daughter:

Case Study Delay: "Who is Brave Enough to Pick on My Daughter?"

Delay is a young woman with full-blown AIDS. She is taking medications but is very ill. Her status is widely suspected, and many wish to discriminate against her. When she met with researchers, her father insisted on accompanying her, and continually interjected about the work he does to keep his daughter safe. According to Delay's father, "people see my daughter and they think she has AIDS, and so the whole family feels ashamed. I always said that they would talk, and they do, but they had better not come near her. If they try and make trouble, they had better remember that I am the head of a war alliance. I will kill that person. My father before me was a war alliance head, and so am I. If they try and make trouble with my daughter I will make war with them." Delay sits at home all day long. She is very thin, and has multiple sores on her skin, and requires special food and care. Her family provides this for her. Her father is a health worker and has access to medicines. His primary job, though, is to defend her against the community: "There is no discrimination," he said, "because I say so. Who is going to be brave to pick on my daughter? I am nurse Mr. Hadigo, I am a sub-commandant in the independence group OPM and so people are not brave to pick on

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my daughter. No one hits my family. I am a member of the West Papua Association. I am a well-known person around here. Who is brave enough to hit my child?"

It can also be particularly beneficial for an ODHA if a health worker is a close family member. Several respondents noted that they felt truly cared for with double support from a single person:

My older brother (*kakak*) is a *mantri* and he always helps me and gives me advice, he said "I'm a *mantri* and I often help other people, so why you, my relative, why won't you change? You have to change your behavior." But I didn't listen to him.

Another respondent described how her husband's family always supported her in all ways:

If it was time to eat, my husband's older sister always prepared food, and my husband's brother also helped. With them helping I never had problems with food and they never got angry. As long as we stayed near my husband's family, usually they took care of all problems within my family and the household.

In sum, cultural values in the highlands are complex. Responses to ODHA are rooted in long-standing ideas about contagion and epidemics. Family is essential to providing some degree of protection to ODHA – without close family, cultural values of ostracism and discrimination can have a devastating impact.

6. Gender, Social Worth, and Stigma

One of the key goals of this study was to look at gendered experiences of stigma. Evidence has shown that women are adversely affected by stigma in epidemic areas in other parts of the world. Women display a general unwillingness to disclose their status for fear of being harmed or scorned (Bond et al. 2002). Women fear being shunned by their husbands and family upon disclosure of their HIV positive status. The contrast between men and women is important: studies have shown men are more likely to share their HIV status with their wives in the expectation of a supportive response, whereas women are afraid to disclose for fear that this might precipitate divorce, violence, or that their husbands would then tell others (Bond et al. 2002:353; Adejiyugbe et al. 2004).

The results of our study suggest that men and women experience stigma and discrimination in different ways. By and large, both men and women were afraid to disclose their status, felt their status was their fault and felt ashamed of their status. However, Table 2 shows the results of key questions about stigma's effects on self-stigmatization, that is, on feelings of self-worth and personal well-being.

Table 2. Strongly articulated statements of self-stigmatization, by gender

Strongly articulated statements of self-stigmatization, by gender		
Self Stigmatization	Men (n=13)	Women (n= 15)
Very afraid to disclose status	11 (84%)	10 (66%)
Feel strongly their status is their fault	9 (69%)	12 (80%)
Feel strongly ashamed of themselves	8 (62%)	13 (87%)
Feel strongly dirty or unworthy	4 (31%)	12 (80%)
Strongly do not feel respected or needed	3 (23%)	10 (66%)

Table 2 shows significant differences in how men and women felt about themselves. While both men and women were quick to blame themselves for their HIV-positive status, and were afraid to tell others, men were far less likely to have negative feelings about themselves. Men did not strongly articulate feelings of being “dirty”, and they also

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continued to feel respected and needed in their community. In contrast, women are more likely than men to say they feel “dirty,” unworthy, and disrespected.

Dominant themes for both genders was 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 it succinctly:

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

These feelings and concerns appear to affect how men and women respond to VCT and medications, as the following sections show.

Men's Responses: Social Status is the Most Important Thing

Men appear to have less difficulty hiding their condition, appear to spend less time worrying about keeping up appearances, and appear to have to do less to maintain their sense of social worth. 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.

Men talk in a way that suggests they were choosing to make changes to their life. Another respondent described decisions in terms of personal choice:

Since I got sick I stepped down from my job as church committee member because I behaved badly. I have stopped my committee work. But I still do the other church work such as gathering money or pigs for the church...I stopped working on the church committee on my own initiative.

Some men also described a ready willingness to go to the hospital or clinic and obtain medications. They appeared to be more comfortable using health services to get tested, and appear to be willing to listen to health care workers' suggestions on how to adhere to ARVs:

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.

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.

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However, many more men appear to avoid seeking help from VCT centres. This may be linked to status. Men are more likely to hide and withdraw in remote locations. However, men are likely to have social support for this level of withdrawal. Men have more developed networks in the wider community and therefore have more options, but also more to lose if everyone knows.

Women: Social Belonging is the Most Important Thing

Women appear less able to contain the negative effects of disclosure than men. When women were the targets of discrimination, they were really targeted. Our results show women take great care to protect themselves from being stigmatized, and they do so through careful attention to secrecy. Researcher Gerdha Numbery situates women's determination to protect themselves and to remain socially connected from the context of family and culture.

Numbery argues first we need to understand women's responses in the context of close family. Women's material worth affects how women respond to their HIV-positive status. The family is concerned with the gain they may get from women through brideprice payments obtained when she marries. The family is concerned with their reputation, and with wanting a young woman to appear to be a desirable mate. Thus there is a strong social imperative to behave and appear "normal" in order to avoid judgments or problems.

Women's concerns about respect are strongly tied to their role as potential provider of brideprice. Several women said a decrease in physical well-being was a threat to good relations in the family. Being criticized for their weak bodies made them feel not worthy. The following three statements by three separate women show the strength of this theme:

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'm not taking medicine so I got thin very quickly, and I have no desire to eat. 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)". I want to take medicine again, but it's too expensive. 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.

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Second, Numbery suggests women choose secrecy as the best way to avoid stigma. If women's behaviour deviates from the norm, they are likely to remain closed mouth about their status. They are also likely to keep secrets if their behaviour is perceived as deviating from the norm even it is not. Gossip is a major concern:

Everything is a secret because in Lani culture, people talk behind other people's backs. They will say don't meet up with that person, don't go out with him, don't eat his food, don't sleep with him. Then they will go and spread the story far and wide.

Our results show that a woman who does not deviate from the norm is more likely to confide in her husband than women who fear their reputations have been damaged. Women also keep secrets because they want to avoid judgments along religious lines. Women whose parents or husbands were involved in church matters were extremely concerned to keep secrets. Women also keep secrets to avoid involving her family and her husband's family in negotiations around cultural sanctions – e.g. payment of fines for making someone sick. And women keep secrets because they want to avoid punishments, in particular physical violence at the hands of their husbands or their fathers.

Last, Numbery argues women respond by choosing secrecy because they want to avoid ostracism by the family. Ostracism can happen when a family is concerned to maintain their good name, especially in church circles. If a woman goes alone to the clinic or the hospital and is seen she may be ostracized: the woman is shunned, limited in her movements, and mocked.

As a result, the women we interviewed are 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 woman only revealed their status to their boyfriend or husband if they had already paid the brideprice to her family. If they told before brideprice was paid, they would risk banishment by her husband, so they kept this information a secret.

Women also draw on a strong determination to remain active, contributing members of society. Women worked hard to maintain their secrets. The following three quotes show this strong pattern:

They all suspect something, so I have changed my behavior so I don't lose my husband. Before I got sick, if I did something wrong I always ran away to my mom's house but I don't do that anymore. 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. Because of this, I don't want anyone to know I have HIV. So that

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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.

If I feel sick, I hide it, if I am working by the river from morning to night. But when it is noon I am already tired, my head is dizzy, I want to sleep, I can't tell anyone because he will get mad, so I have to say to my husband like this, "Ayoo...husband, I want to go and buy some vegetables, or I want to go and clean some clothes." Then he says I can go, I get permission and then I go home and rest.

Women on ARVs maintain secrecy about their drug regimen in quite specific ways. Many of them obtain medications secretly, by dealing with NGOs who pick up and hand out medicines for women, instead of going directly to hospital. Several women said that if they had to go to the hospital for drugs they would not go. NGOs allow women to actually successfully be on ARVs. 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 by their presence there (e.g. at a pharmacy). They hide medications in a safe, personal space within the home, and take them secretly when everyone is out. They do all of these things to maintain their social role as valued members of their family and community.

Gender and Health Care Access: Men Can Get Help More Easily

Our results show men and women do not respond to testing and medications in the same way. Table 3 shows usage of health care services for HIV testing by gender in the town of Wamena. While within the province of Papua the numbers of men and women who test as HIV positive are roughly equal, in the highlands, we find a strong pattern: more men get HIV tests than women.

Table 3. Gender of patients undergoing HIV testing at three Wamena test locations, cumulative up to May 2010

<u>Gender of Client</u>	<u>Number Tested</u>	<u>Percentage of those tested</u>
Male	476	60%
Female	305	38%
Child under 14	19	2%
<u>Total</u>	<u>800</u>	<u>100%</u>

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Table 4 shows that more men test positive than women because more men are getting tested than women. However, Tables 3 and 4 identify a significant gap in service provision: there are significant numbers of HIV-positive women who are not seeking out testing.

Table 4. Gender of clients who qualify for ARV therapies in Wamena, cumulative up to May 2010

<u>Gender of Client</u>	<u>Number qualifying for ARV</u>	<u>Percentage of those qualifying for ARV</u>
Male	334	62%
Female	195	36%
Child under 14	10	2%
<u>Total</u>	<u>539</u>	<u>100%</u>

Despite the fact that more men are eligible for ARV therapies, we find in Table 5 that women appear more likely to take up ARV therapies than men.

Table 5. Gender of persons who have ever started a course of ARV in Wamena, up to May 2010

<u>Gender of ARV adherent</u>	<u>Number on ARV</u>	<u>Percentage of those on ARV</u>
Male	44	52%
Female	41	48%
Child under 14	0	0%
<u>Total</u>	<u>85</u>	<u>100%</u>

Almost half of the people on ARV are women even though fewer of them have been tested than men. Lack of access to therapies may partially explain gender differences. Men are more likely to be mobile and can visit distant towns without suspicion, whereas women may find they have less freedom of movement and therefore less chance to seek out testing. Mobile testing services would seem to be a priority if the health sector wishes to provide equal access to testing for everyone.

8. Health Care and Stigma: Race, Values, and Respect

Access to adequate counselling, testing, drugs and support for ODHA across the highlands is dismal. Most of the region remains without service. In the areas where there are VCTs and ARVs available, uptake of those services remains low. Although the Indonesian government boasts an ARV uptake of 30% of HIV-positive persons in the country, in the highlands only around six percent of known ODHA appear to access ARVs. This number is shockingly low, and suggests major problems with health service and delivery.

The type of services offered in the highlands region appears to be a significant barrier to access. An important study by Morin (2007) outlined problems with VCT services and uptake in Sorong, Papua. In particular, Morin noted fear of stigma was a significant problem, and lack of information about VCT also impeded uptake. However, these concerns remain largely unaddressed in highlands Papua in 2010. ODHA continue to display overall low levels of knowledge and awareness of HIV and the services available through VCTs. However, our respondents also noted specific problems with the quality of services that were offered to them. They identified three key concerns: race, stigmatization by health workers, and problems with confidentiality.

Race

The vast majority of staff in major health centres facilities are migrants. They often possess little knowledge of Papuan culture or values. Indigenous staff do have a place providing primary health care in rural health centres, but many employees in VCT centres are not indigenous. Patients overwhelmingly vote with their feet – when a clinic in Wamena opened its doors in 2007 offering 100% indigenous staff service (with the exception of the missionary physician), they were flooded with patients. According to numerous respondents, indigenous patients far prefer receiving treatment from indigenous staff.

Indigenous health care workers felt that the lack of understanding and empathy of migrant workers meant they would not respect confidentiality. Nosa, a Papuan woman who is the case manager for a VCT, and a deeply empathetic person, feels that when a non-Papuan is offering help, by and large Papuans won't accept the service:

Papuans will say, "Better I not get treatment there, because they might kill me. I don't want to be cared for under them, better just die." And then they seek care from the pastor or minister instead, asking for them to pray for them, so they can die in peace.

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Values

Our research shows that some health care workers actively stigmatize patients who are HIV positive. We asked 15 health care workers who work in VCT or in related health care activities in Wamena to complete a stigma scale, in which they were asked to respond to statements about HIV-positive persons. As Table 6 shows, some health care workers strongly stigmatize ODHA.

Table 6: Number of health care workers in Wamena who agree with stigmatizing statements about HIV-positive persons

Stigma Statements about ODHA	Agree	Percent Agree	Disagree	Percent Disagree	Total
1. People who have HIV/AIDS are dirty	3	25%	12	75%	15 (100%)
1. People who have HIV/AIDS probably feel ashamed	12	75%	3	25%	15 (100%)
2. People who have HIV/AIDS have to accept limitations being placed on their activities	13	87%	2	13%	15 (100%)
3. The behaviour of people who have HIV/AIDS is wrong and they will receive an appropriate form of punishment	5	33%	10	66%	15 (100%)
4. People who have HIV/AIDS should be shunned	3	25%	12	75%	15 (100%)

Some health care workers who have received VCT training agree with overtly discriminatory statements such as that ODHA are dirty, should be shunned, and should receive a punishment. Almost all workers agreed with more subtly stigmatizing statements, such as ODHA having to accept limits on their behaviour or assuming that ODHA will feel ashamed of their status.

Respect

A third reason for low service usage is the issue of confidentiality of the client. Optimally, voluntary counselling and treatment is supposed to help reduce stigma by allowing the client to keep his or her status secret, or to control how, when, and to whom this information is disclosed. The three “C”s—convenience, confidentiality and credibility—are the cornerstone of effective responses to HIV (Angotti et al. 2009). Unlike Morin’s 2007

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study in Sorong where VCT workers appear to respect confidentiality, in highlands Papua, confidentiality is routinely violated, as one respondent noted:

Confidentiality? It doesn't work at all. In fact, it might as well not exist.

In interviews with VCT staff, counsellors and office support staff agree it is hard to maintain confidentiality in their clinical practice. Health care employees are widely seen as eager to gossip. Some workers are willing to acknowledge that they are not very good at keeping secrets.

Health workers tend to look beyond themselves to structural problems with VCT and ARV services. They see inconsistent recording systems. They feel training focuses on getting people on medications rather than teaching respect for their rights. They feel Papuan practices and concerns are different than the rest of Indonesia but materials from Indonesia are what are presented in training workshops. Dealing with complex Papuan values is not taught in workshops. Instead, the staff learn about irrelevant case studies from other parts of Indonesia such as how to deal with intravenous drug user cases, youth carrying knives, and clients attempting to assault counsellors. As one frustrated employee said:

Here in Papua we get Papuan people who gasp 'I'm going to die' after hearing they are HIV positive. Then they leave and we never see them again. We have different problems here than the rest of Indonesia.

They also feel frustrated with the standard of trying to visit an ODHA's home to oversee food and care within the family, because this violates cultural standards of secrecy. They hear patients complain that they have HIV but still have to pay for drugs. They hear patients complain pharmacies are expensive, and are run by doctors from the hospital for a lucrative private business.

Last, health workers say that ODHA prefer services by NGOs to services at hospitals or clinics. NGOs and clinics run by indigenous people, which are used and trusted, should be seen as a valuable initiative. For women in particular, when NGOs provide ARVs in discreet locations in a respectful manner, it allows them to actually be on the drugs. NGOs offer women and men protection from the stigmatizing practices of health workers, and from the potential stigma of being seen at the hospital or clinic.

9. Conclusion and Recommendations

This report has shown significant challenges exist to ODHA quality of life in highlands Papua. Stigma and discrimination are rife, and include self-stigmatization, social ostracism, institutionalized stigma, and structural inequities. Stigma strongly affects how ODHA view their families, their communities, and their health care services.

Undeveloped or inadequate services, racist health care, stigmatizing health care workers, lack of information, and inadequate support: all limit the ability for persons who suspect they are HIV-positive to obtain care, testing, treatment and support.

Lack of information about HIV and ARV is a significant problem. Researcher Ibrahim Peyon noted that Papuans have internalized a lot of incorrect information that propels discrimination. Fears around contagion via toilet, food, and clothes etc make it hard to acknowledge and accept ODHA as part of social life, and for an ODHA to accept him or herself. All of our researchers noted ODHA's deep concerns with keeping secrets because social repercussions at the level of clan or community based on misinformation can be brutal. There is always a very strong possibility of character assassination.

Developing interventions to allow ODHA to participate as valued members of their community is key. Researchers Castro and Farmer (2005) and many others have shown that stigmatizing practices decrease when a person has regular access to ARVs. Offering ARVs can help reduce stigma, but only if the health care provider respects the patient, their cultural values, and their personal strategies for coping. ARVs can work, but only if an ODHA is able to organize the medication so that cultural patterns of secrecy can be respected. In highlands Papua, gendered responses, an overwhelming concern with secrecy, and a fundamental mistrust of health services are the three most important factors shaping ODHA experiences of stigma and discrimination.

Recommendations

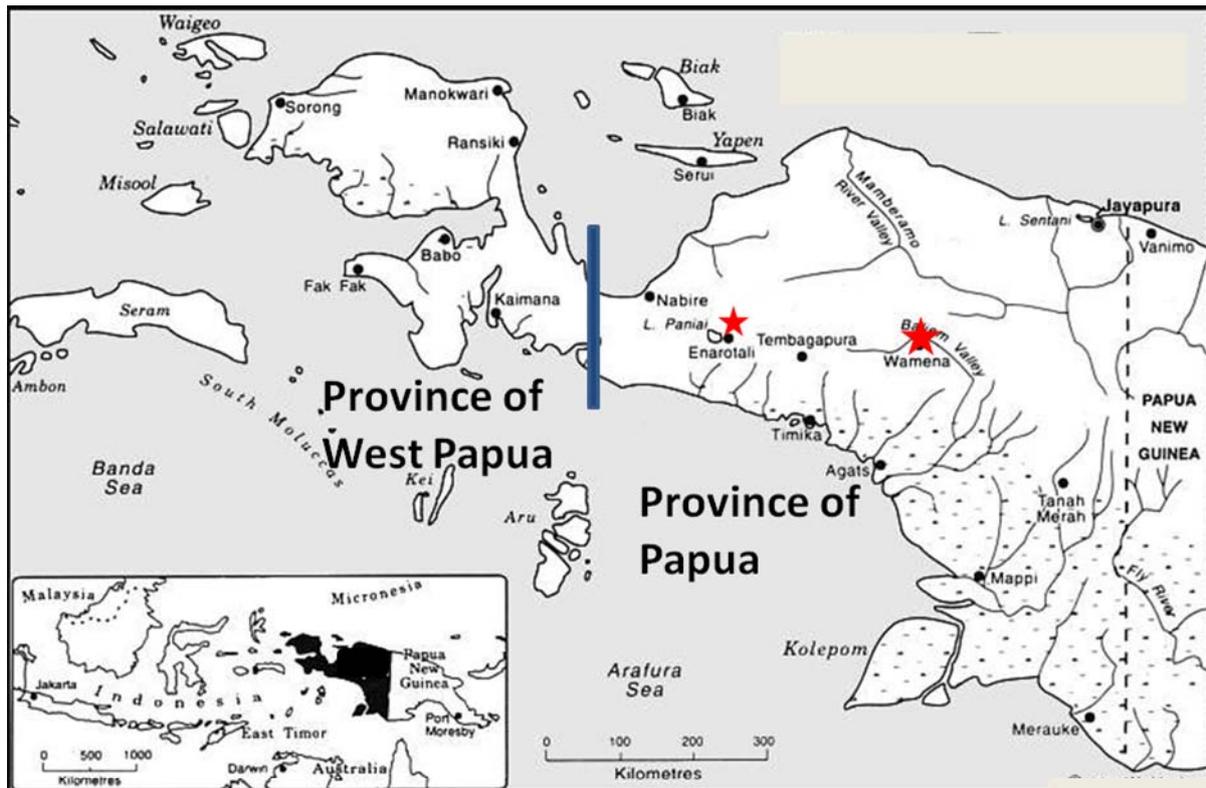
- Acknowledge the inadequate structural interventions currently in place. Place priority on establishing care, support and treatment services in high risk regions, such as those within driving or walking distance to main centres.
- Acknowledge the role of religious leaders in promoting stigma against ODHA. Develop concrete measures to provide awareness training for religious leaders.
- Develop concrete measures to provide awareness training for migrant health care staff about the impact of ethnicity on how patients perceive care.

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- Acknowledge cultural factors can play a role in how ODHA respond to diagnosis. In particular, strong values around secrecy and existing stigmatizing practices are quickly drawn upon in responses to a diagnosis of HIV. Ostracism is a recognized response to serious illness.
- Provide respectful care and support services that can be accessed through public or NGO facilities, rather than trying to involve the family of ODHA or visit ODHA homes to oversee domestic conditions. This will minimize current fears that services are too invasive.
- Promote ODHA care through promoting tribal solidarity. Rather than encouraging a global model of confidentiality that emphasizes the individual, encourage communication about stigma from the perspective of clan survival and prosperity. Work with sustained strong identities aligned along the lines of clan and tribe.
- Acknowledge gender differences in how women and men respond to HIV diagnosis and treatment. Provide more information about HIV testing directed to women, and make it easier for women to access testing.
- Acknowledge the excellent work done by NGOs and clinics that provide support in discreet, respectful fashion. Provide more assistance to NGOs that provide treatment.
- Acknowledge that men appear less likely to take up treatment than women. Assess new strategies for providing support and treatment for men.
- Acknowledge the power of health care workers to increase stigma through their behaviours and actions. Promote respect more fully in health care worker training.
- Acknowledge the importance of ethnicity in shaping how Papuan ODHA respond to their HIV status. Acknowledge the particular concerns of Papuans around receiving treatment by non-Papuan health care workers. Ensure that Papuans are given priority in training activities to allow for a majority of care, support and treatment providers to be indigenous Papuans.
- Provide more rewards for health care workers who are successful in treating ODHA in order to encourage them to remain in their positions.
- Promote the use of Papua-specific materials and case studies in training. Use realistic scenarios, such as community-based discrimination, religious ostracism, or individual concerns around secrecy.
- Respond to very low rates of HIV testing and high levels of fear by training more Papuan outreach workers to spread information about counselling and therapies and how to access them.
- Provide more support for the NGOs that provide excellent care, support and treatment for ODHA. Promote much greater participation of Papuans in the care and support of ODHA.

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Table 8: Map of the Province of Papua



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