

Living with HIV and cultural diversity in Sydney

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MONOGRAPH 4/2005

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Summary

Key findings

- The majority of participants were diagnosed with HIV either by the Department of Immigration and Multicultural and Indigenous Affairs as part of the health requirement for permanent residency, or as a result of seeking treatment for symptomatic infection.
- HIV infection was perceived as a terminal illness. The majority of participants were not aware of the differences between HIV and AIDS.
- The mother tongue was important for making sense of HIV as a chronic condition rather than a terminal illness.
- Access to health care services was affected by participants' immigration status. Those on certain temporary visas were not eligible for Medicare.
- Disclosure to family and ethnic communities was purposeful and motivated by the interdependence of individuals with their social networks. Participants positioned themselves in a way which allowed them to protect themselves and their families from stigma and discrimination and, at the same time, get the support they needed.
- Confidentiality was of utmost importance.
- The preferred form of support through bi-lingual, bi-cultural co-workers represented closeness and distance simultaneously: closeness through one-to-one support from someone from the same cultural background and in the mother tongue; distance through being outside participants' social network of family and friends. This enabled participants to talk about their concerns and at the same time maintain silence about their HIV status with family and friends in the country of birth and in Australia.

Recommendations

We recommend the following strategies based on the findings of this study:

- That support and information on living with HIV/AIDS be available, where possible, in a range of community languages and/or plain English. This study showed that mother tongue was critical to the lives of the people living with HIV/AIDS from culturally and linguistically diverse (CALD) backgrounds.
- That the cultural competence of HIV/AIDS services be enhanced to respond more appropriately to the cultural needs of people from diverse backgrounds who are living with HIV/AIDS. This study showed that when people from CALD backgrounds who were living with HIV/AIDS accessed services, significant cultural issues arose: for example, around disclosure and preferred options for support.
- That awareness of HIV/AIDS in the Australian context be raised in CALD communities using ethnic media and other community structures where they exist. HIV/AIDS continues to be a highly stigmatised health condition in CALD communities and is often grounded in people's experiences of HIV/AIDS in their country of birth.
- That, when HIV diagnosis is made as a result of an Immigration health check, pre-and post-test counselling be strengthened. Immigration health checks were the source of a positive diagnosis for some participants in this study.
- That targeted HIV testing be promoted among priority CALD communities. In this study, symptomatic HIV infection was the motivation for HIV testing or presentation to a health service for many people from CALD backgrounds who were living with HIV/AIDS.

- That additional gender issues be taken into account in the delivery of health services to women from CALD backgrounds who live with HIV/AIDS. The women in this study experienced additional gender-related barriers when accessing health services.
- That social research be carried out to guide HIV prevention efforts among priority CALD communities and GPs in those communities. HIV/AIDS surveillance highlights an overrepresentation of people living with HIV/AIDS among Asian and Sub-Saharan African communities. This study has highlighted the social contexts of people from CALD backgrounds who live with HIV/AIDS within their ethnic/cultural communities.
- That further research using culturally appropriate methodologies be carried out to expand the evidence for interventions with and for people from CALD backgrounds who live with HIV/AIDS. This study was the first of its kind to investigate the lived experiences of such people.

Background

In the National HIV/AIDS Strategy 1999–2004, people from culturally and linguistically diverse (CALD) backgrounds were identified as a group with specific requirements for HIV/AIDS-related education, prevention and health promotion. Individuals in this group may belong to one or more priority groups identified in the strategy: gay and homosexually active men, injecting drug users and people living with HIV/AIDS.

Surveillance data show that people born in non-English-speaking regions of the world accounted for 20% of HIV notifications in Australia in 2002–2003 (McDonald, 2004).¹ People born in Asia and Sub-Saharan Africa were overrepresented and made up 13% of these HIV notifications.

The Australian national pattern of HIV/AIDS among people born in Australia and in other English-speaking regions is broadly similar in that male homosexual exposure is the dominant mode of transmission and age-standardised rates for an HIV diagnosis are among the lowest. In contrast, the pattern of HIV/AIDS among people born in non-English-speaking regions differs in that there is a much higher proportion of heterosexual exposure, a higher proportion of women living with HIV/AIDS, and age-standardised rates of an HIV diagnosis are among the highest.

In the period 1999–2003, 20% of new HIV diagnoses in Australia were attributed to heterosexual contact: among heterosexually acquired cases in this period, 40% were born in Australia, 26% in sub-Saharan Africa and 17% in South-East Asia. This pattern is further confirmed by a detailed look at 529 cases of heterosexually acquired HIV: 33% of infections occurred in people from high-prevalence countries and a further 26% occurred in people who reported having had a partner from a high-prevalence country.

While the annual number of HIV diagnoses among women has remained

stable over the past ten years, an increasing proportion of such diagnoses has been associated with heterosexual contact in a high-prevalence country or with a partner from a high-prevalence country.

In 1999–2003, 20% of AIDS diagnoses in Australia were made among people born in non-English-speaking countries. Late diagnosis with HIV is strongly associated with the often overlapping categories of ‘people born in non-English-speaking countries’ and ‘men and women heterosexually exposed to HIV’. A greater proportion of late presenters were born in Asia, Southern Europe or South America. This suggests cultural and linguistic barriers to accessing information about HIV and HIV testing. While there is no HIV/AIDS research in Australia relating to heterosexuals from CALD backgrounds, research among CALD gay men has found them to be twice as likely as their Anglo-Celtic counterparts never to have been tested for HIV (Prestage et al., 2000; Mao et al., 2003).

Late presentation with HIV resulting from poorer access to HIV testing has major public health implications because it results in delay in the uptake of antiretroviral treatments and delay in behaviour modification (Hocking et al., 2000). Among those who are diagnosed with AIDS-defining illnesses, one determinant has been country of birth. The incidence of tuberculosis and cryptococcosis was significantly higher among people with HIV/AIDS born in Africa and Asia (Dore et al., 2001).

The importance of language and ethnicity when it comes to knowledge about HIV, about prevention and about available services has been highlighted by researchers in the US, Europe and New Zealand. Studies in the US showed substantial differences in AIDS-related knowledge between English- and Spanish-speaking Hispanics and, associated with this, misconceptions about the risk of having or acquiring HIV (Miller, 2000). Racial minorities in the US were less knowledgeable than white Anglo-

¹ All figures in this section are from McDonald, 2004. Figures do not include ‘Other Oceania’ as the vast majority or all are born in New Zealand.

Americans about HIV/AIDS generally, key aspects of prevention, and antiretroviral treatments (Scott et al., 1998; Ebrahim et al., 2004). In a study of Latina women, access to health services was directed by agencies rather than self-directed. Their access to these services was also affected by their immigration status (Takahashi & Rodriguez, 2002).

The need for culturally and linguistically appropriate HIV-prevention education was also highlighted in a study of seasonal workers in Switzerland (Haour-Knipe et al., 1999). And, among refugees from Sub-Saharan Africa in New Zealand, language difficulties were a barrier to seeking health care (Worth et al., 2001).

There is a significant body of Australian research that provides insights into the experiences of people living with HIV/AIDS in Australia. However, there is no research that provides insights into the lived experience of people with HIV/AIDS from CALD backgrounds in this country. For example, successive HIV Futures studies of large samples

of people living with HIV/AIDS have not successfully recruited participants from CALD backgrounds. In the most recent survey, HIV Futures 4, less than 1% of the sample spoke a language other than English at home (Grierson et al., 2004).

Our study, the first of its kind, was funded to address this significant research gap and was concerned with the lived experience of HIV-positive people from CALD backgrounds in Sydney. We wanted to investigate the interrelationship of living with HIV and belonging to culturally diverse groups outside the Anglo-Celtic mainstream. The focus was on common issues across cultures and ethnicities. The study is based on the understanding that individuals live within complex historically and culturally constructed social relations, that human actions and relations are embedded in social structures, and that history and culture shape the potentials as well as the constraints of people's lives (Dowsett, 1996).

Method

Participants were recruited among the clients of the Multicultural HIV/AIDS and Hepatitis C Service (MHAHS) and a sexual health clinic in the Sydney metropolitan area. The research methods were selected to ensure that barriers to participation, and any possible negative consequences to participants, were minimised.

Data were collected in semi-structured, open-ended interviews in participants' language of preference. For interviews in the mother tongue, participants could choose an interpreter, or language support from their bilingual co-worker at the MHAHS. The interpreters were professional interpreters of the NSW Health Care Interpreter Service. Those who requested an interpreter had used interpreters previously and were familiar with this kind of interaction.

To provide consistency across interviews, an interview guide was developed by the researchers and the project advisory group, which consisted of professionals working in the field. Interviews typically started with a question about participants' reasons for coming to Australia and the circumstances of migration. They then explored the circumstances and meaning of HIV diagnosis, access to information about HIV/AIDS, their experience of using the health care system and support services, and issues of disclosure to family and ethnic communities.

The study was approved by the Human Research Ethics Committee of the University of New South Wales as well as the ethics committees of the Central Sydney Area Health Service and the South Eastern Sydney Area Health Service.

Interviews were audio-recorded and transcribed, retaining participants' own expression. Identifying information was removed from the transcripts or changed to ensure the anonymity of participants. Transcripts were coded for major themes. These were discussed and revised by the researchers and professionals working in the field. These themes form the basis for this report.

Description of the sample

Twenty-nine participants agreed to be interviewed. They ranged in age from 29 to 58 (median age 39). There were seven women and 22 men. Of the men, 15 identified as gay and six as heterosexual; one man provided no information. All female participants identified as heterosexual. Twenty-eight were born overseas and had arrived in Australia between 1973 and 2001. One participant was born in Australia and identified as Greek-Australian (see Table 1). The participants had been diagnosed with HIV between 1984 and 2003.

Table 1: Region of birth

	<i>n</i>
Asia: Cambodia, China, Hong Kong SAR of China, Indonesia, Malaysia, Thailand	16
South America: Argentina, Bolivia, Chile, Colombia, Peru, Uruguay	8
Europe: Cyprus, the FYR of Macedonia, Serbia and Montenegro	4
Australia	1
Total	29

Four participants spoke English at home, five spoke both English and their mother tongue, and 20 spoke their mother tongue.

Six participants had one to six years of elementary schooling, 12 had up to 12 years of schooling and eight had tertiary qualifications. Thirteen were in full-time or part-time employment or self-employed. One studied full-time. Four did volunteer and casual work. The remainder were on government benefits. The women were typically home makers. One worked full-time. Eight participants had children.

Twelve participants were long-term permanent residents or Australian citizens. Five had uncertain immigration status² when they arrived in Australia but were

² For the purposes of this report we do not distinguish between immigrants who came under the migration program (for skilled and family migration) and those who came under the refugee program (for refugees and others in humanitarian need) (<http://www.immi.gov.au>, 13 November 2004).

now permanent residents. One participant had arrived on a temporary visa and had had his appeal for permanent residency rejected. Two participants had had temporary visas when they arrived but provided no information about their current immigration status. Nine still had uncertain immigration status, sometimes because of their HIV status: they were on various temporary visas³ and were often waiting for a decision from one of the relevant review tribunals.⁴ For some, this state of uncertainty had lasted several years already. Since participating in the study, one of those on a temporary visa has been deported and one has been granted residency. The vast majority of participants were legally resident at the time of participation.

³ There are more than 90 different kinds of visas in Australia with different entitlements and restrictions (<http://www.mrt.gov.au/operations.html>, 29 October 2004). By 'temporary visa' we mean any visa that does not entitle its holder to reside in Australia permanently and with the full rights of a permanent resident.

⁴ Decisions of the Department of Immigration and Multicultural and Indigenous Affairs can be reviewed by three independent tribunals: the Migration Review Tribunal, the Refugee Review Tribunal and the Administrative Appeals Tribunal (<http://www.immi.gov.au/facts/09litigation.htm>, 13 November 2004).

Findings

1 Diagnosis

Circumstances of diagnosis

Three gay men had tested HIV-positive in their country of birth and knew their serostatus when they came to Australia. The remainder (26) were diagnosed in Australia. Regular testing was reported by only three gay men. Two main themes characterised the circumstances of diagnosis in Australia: diagnosis was made as part of the health check required by the Department of Immigration and Multicultural and Indigenous Affairs for all applicants for permanent residency, or as a result of seeking treatment for symptomatic infection.

Each participant who arrived in Australia on a temporary visa and subsequently applied for permanent residency had to have an HIV test as part of the health requirement (Department of Immigration and Multicultural and Indigenous Affairs, 2003, 2004). For participants diagnosed in this way there was no pre- or post-test counselling.

'... diagnosis was made as part of the health check required by the Department of Immigration and Multicultural and Indigenous Affairs ... or as a result of seeking treatment for symptomatic infection.'

'I came to Australia [with my two children] as a [visa type] and then I applied to live permanently in Australia ... At that time I applied that I want to take my visa, I want to take my children to continue their studies ... in Australia And then the paperwork went through and then the last part they asked me to do the blood test and then one day they call me to tell me about my results and they told me that I'm positive with this and then I feel shocked. I fell unconscious right away ... I did not have any idea that I might have this. So unpredictable, it make me

really shock ... And since then I cannot sleep every night. I still can hear the voice saying that I'm positive with this type of disease.' (*Cambodian woman*)

The diagnosis jeopardised participants' prospects of staying in Australia. At the same time it was now difficult for them to return to their country of birth because of their serostatus, because of the political situation they sought to escape, or both.

CO-WORKER: He applied for a refugee visa on the basis that he can't go back ... to his own country, which is Croatia, in former Yugoslavia. Because at that time [1993] there was a war in former Yugoslavia, Croatia ...

PARTICIPANT: Because I'm from Serbia, I live in Croatia, I have permanent residence [in Croatia], I can't go back! Plus they find I'm HIV-positive.

CO-WORKER: Because he was a Serbian living in Croatia. That's dangerous.

PARTICIPANT: And when I'm going to the doctor to search my health, everything's HIV. (*Serbian gay man*)

The second theme was diagnosis with symptomatic infection. Participants reported a variety of symptoms which caused them to seek medical help: long-term flu, rash, itchiness, weight loss, candidiasis, cryptococcal meningitis, pneumonia or, as one participant called it, 'pneumonia specific to the person living with HIV', and dementia. One had a CD4 count of 40 when he was diagnosed. Some reported simply that they were so ill that they had to be admitted to hospital.

There were issues specific to women. Those who were not diagnosed as part of the immigration process were tested because their husbands had HIV/AIDS. In addition, women's access to health care services was often controlled by their husbands. Some men refused to take their wives to a clinic, which delayed diagnosis for some. Because of their lack of English and their lack of familiarity with the health care system, women depended on their husbands or another English-speaking person.

'When we first arrived here I knew that he [ex-husband] came here to this clinic [sexual health clinic] but he did not tell me what for and then a few times later when he was break down I knew that he has some sort of health problem and myself one day I went to see my family doctor who can speak some Cambodian and I asked him to refer me to this clinic ... I ask him [ex-husband] to take me here to the clinic but he refuse. So I try to come by myself and then after the test I found positive. He can speak English and I can't ... My ex-husband can speak English but I can't rely on him. He refuse to take me anywhere, even to come to this clinic. He refused to take me here. So ... I ask someone else to take me here. After four months in Australia I don't know anyone. I have no relatives at all.'

(Cambodian woman)

Women also reported discriminatory treatment from health care professionals, who made assumptions about their sexual and drug use behaviour.

'When I started feeling sick with the flu [seroconversion illness] he [doctor] said that because of the symptoms it could be this condition [HIV], 'But I don't think so because you are a lady.' Not thinking that it was HIV. And later on, when he discovered it, he said, 'I don't know who the gentleman is and I don't want to know.' And then the same country! That GP happened to be from Uruguay too [as was her husband]! I never went back to that GP.'

(Argentinian woman)

HIV knowledge at time of diagnosis

All participants knew about AIDS but only a few knew about HIV. Those who knew people with AIDS in their country of birth saw how they were stigmatised in the local community and that they died. This coloured the meaning of their own diagnosis.

'They did explain to me that I'm positive of HIV but in my language [Khmer] I don't have the word for HIV. We unfortunately presume that it's AIDS. Yeah, and he [doctor] tried to explain to me, "Not yet, you just started." When I was in Cambodia I saw the information, the brochure about this. They just call it AIDS ... AIDS disease, not HIV, and we believe that it's terminal. It means when you've got it you won't live very long.'

(Cambodian woman)

Reaction to diagnosis

Participants' reaction to their diagnosis was grounded in their knowledge about HIV/AIDS from their country of birth: AIDS was a terminal disease. The first thought for many was 'death'. The emotional reaction was shock and disbelief. Participants did not perceive themselves 'at risk'. They described themselves as feeling lost, disoriented and

without hope for the future. Some described a complete social and emotional shutdown.

CO-WORKER: She remember when she was first diagnosed the doctor asked if there be someone, you know, like staff come and talk and she said they [she and her partner] refused to meet anyone else. Apart from the doctor they refused to talk to anyone else ... She said she was stunned. She just couldn't think. Dark everything. Dark. And even looking back she can't think of anything. It was just, you know, completely dark ... She was always crying alone.

(Thai woman)

Those who were new to Australia and without family and friends felt utterly isolated and alone.

'Terrible, because in that time I feel very isolated. I have no family, no friends, nobody here and I just apply for permanent resident. I end up having to wait for almost three years. The emotional situation was very bad ... because there was no support. That time I was living very hard. I can't express myself, for example ... Almost nothing. Just a few words in English and no more ... Um, secondly, alone, with no family, no friends, nobody, to find out you are HIV-positive five years ago, it was something that was a big scare. You feel like the whole world is going down, going down. Very hard.'

(Colombian gay man)

Others withdrew voluntarily from their social networks. To avoid shame for themselves and their families, some even contemplated suicide.

'At that time, because I felt that I was isolated, and all I thought that maybe I just end my life and that will be it.'

(Heterosexual man from Hong Kong)

2 Access to HIV-related information and services

Learning about HIV

Participants were on a steep learning curve. Information in the mother tongue immediately after diagnosis was important. It enabled participants to make sense of their diagnosis and to change their perception of 'dying of AIDS' to 'living with HIV'. Language was also an issue when participants with limited knowledge of English tried to make contact with HIV/AIDS services.

'And I call to the number. Then I explain in my very bad English that I need not information, but I need to make an appointment to talk to somebody else. Then that time [name], she make me an appointment with an interpreter. Then in that way start to introduce me to HIV Multicultural Service ... After eight months to be

here in Australia ... For me the only difficulty back in that time was the language. It was the most big barrier experiencing in that time, English. Because everything is in English, English, English. The thing is only a few information in Spanish or other language. Then there was barrier for me to communicate with everybody. Was very hard.'

(Colombian gay man)

'... they need their sympathy and they need their concern ... their concern is worth more than medication.'

GPs were an important source of information and referral to specialised HIV health services and counselling at the time of diagnosis. They also provided ongoing information about treatments and clinical markers. In addition, participants used a variety of general sources of information about HIV: news media, pamphlets by community organisations, the internet, movies, television and their social networks (in the case of established migrants). Some community organisations were criticised for providing too much information about safe sex and not enough on surviving with HIV.

Information needs were not static but changed over time. Some participants wanted to know as much as possible when they were diagnosed; others found too much information at the time of diagnosis overwhelming. Some felt that 'for now I know enough' but acknowledged that their information needs might change in the future.

Participants wanted information in the mother tongue not only for themselves but also for their family members and their ethnic communities at large. Specifically, to lessen the stigma from HIV infection, ethnic communities needed information about the difference between HIV and AIDS, information to dispel misconceptions that HIV could be transmitted through social contact, and realistic information about people living with HIV.

'I want to get the message to the Chinese community that HIV is not a terrible thing, that they do not, you know, racist [discriminate]. And so they need their sympathy and they need their concern rather than—their concern is worth more than medication.'

(Heterosexual man from Hong Kong)

Using health care services

Access to health care services was affected by participants' immigration status. Those on certain temporary visas were ineligible for Medicare. As a result, some delayed testing and seeking medical help for symptomatic infection even

though some intervention, such as HIV testing, could be provided at public sexual health clinics without the need for a Medicare card. They also had problems getting health care after they were diagnosed.

'In [sexual health clinic] I get very bad treatment. The doctor says, "Oh, if you have no Medicare we cannot treat anything." And then they just kick me off, just like—I shocked ... Yeah, shocked. How can a doctor say that? And this is the sexual health centre in [suburb].'

(Thai gay man)

For some, the only way to get antiretroviral treatment was to enrol in clinical trials. For others, the uncertainty of their immigration status affected treatment adherence. They saved any treatment they had in case they were deported because treatment in the country of birth was difficult to get and expensive.

'I am getting prepared ... While the doctors were telling me very carefully not to stop taking your medication at the prescribed times and in the prescribed amount ... I take half of the medication, of course with the risk of getting worse. But because I was having blood tests every four months and also I was, like, controlling my health condition, I saw that nothing like that was happening. So, in the end I have medication for a whole year.'

(Peruvian gay man)

Participants were generally full of praise for the health care they received. However, they also experienced some difficulties. For new arrivals, these were language barriers and not knowing the system: for example, being referred to the right service but not knowing what this service was about, being referred from one service to another without understanding why, and fitting in with business hours if they worked long shifts. The last of these also had negative effects on treatment adherence.

'It is difficult ... in the clinic at [suburb] the doctor only works from Monday to Friday and they only dispense medication on Monday to Friday and if I had to work between Monday to Friday then it's very hard for me to go there and get my medication ... It is my experience for these few years and it—and sometimes I couldn't leave my work and go to get my medication and then I would have no medication to take ... I can't stop this work and find other work because I have to get medication and if I did it I don't have a stable job without the shift between jobs and jobs.'

(Chinese man)

The bilingual co-workers of the Multicultural HIV/AIDS and Hepatitis C Service were important brokers between participants and the health care system. They provided language support, helped participants to make sense of their diagnosis, were a source of referral, helped to deal with government and community agencies and helped to provide information about treatment.

3 Disclosure in families and ethnic communities

The decision to disclose or not disclose HIV status was purposeful and motivated by the interdependence of individuals with their social networks, especially their families. Participants positioned themselves in a way that enabled them to protect themselves and their families from stigma and social ostracism. If disclosure threatened to disrupt social relations, participants chose not to disclose. Individuals' decisions about disclosure were also affected by knowledge of and attitudes to HIV in their ethnic communities. Balancing their own needs for privacy and support and the needs of others motivated participants to be highly selective about disclosure.

Reasons for disclosure were both self-directed and other-directed. Participants disclosed to family members, typically siblings, because they wanted to unburden themselves. They also disclosed because they were no longer able to fulfil their family obligations: for example, to look after ageing parents. This obligation had now to be taken on by a sibling.

'Having thought about it in great detail I decided that I should inform someone and therefore the first person that I decided to tell—to disclose—that will be a family member. I told my elder sister and also my second elder brother; they are both in Hong Kong. Because I thought that I have the obligation to inform them of my problem because I have to take care of my mother.'

(Gay man from Hong Kong)

Similarly, reasons for not disclosing were both self-directed and other-directed. Self-directed reasons included a fear of gossip and forced disclosure, which would eventually reach the family in the country of birth, fear of being labelled as 'immoral' and 'deviant', and fear of social ostracism. An other-directed reason for not disclosing, for example, was saving face for the family.

'If Thai people, if one person knows, and, you know, gossip. They will tell someone and tell, tell, tell. So it's better to stay by yourself, not to let anyone know. "Oh, big news, [professional] in Sydney (details omitted). Oh, he got HIV." You see, in Thailand that's big news ... And my surname, my family surname gone! And I cannot go to university. I lose my family. My mum will lose face ... That is most important, I think. "Oh, your son is gay." ... Her relatives, you know, you have to answer the relatives, "Why, why, why your son is gay?"'

(Thai gay man)

Other reasons were that participants put the needs of parents and relatives ahead of their own and felt that disclosure was a burden to others.

'I've pictured it in my mind a thousand times. She [sister] would break down and cry and cry and cry and cry. And then she would be worried. Like all my friends are. At least the one in Malaysia ... my best friend, he writes me regularly. All the time (unclear) ... you know, "How are you?" That shows how worried they are. So, I must have come to that stage—I don't (unclear) anymore because it's a burden. I'd rather bear it myself than other people worry about me.'

(Malaysian gay man)

Decisions not to disclose were also affected by knowledge about and attitudes towards HIV in ethnic communities. HIV infection was still perceived by many as a terminal disease and participants did not want to be labelled as 'dying'.

'They [Thai community] might not like it if they knew I've got HIV and it might become—yeah, it's like an inferiority complex, you know, you're going to die any time. So, and then, if people find out I've got HIV, people talk about HIV, and, you know, I might become depressed because of hearing people getting worried about me and, you know, always talk about it.'

(Thai heterosexual man)

Where HIV was perceived to be transmitted through social contact, participants did not want to be labelled as 'contagious' and forced into social isolation.

'When I was in Thailand about the New Year time, one of our neighbours, someone in our neighbourhood died of AIDS. And you know, no one went to the funeral of that person, no one helped that family to do anything. They were too scared to touch anything, to go near the place.'

(Thai woman)

Some participants negotiated decisions about disclosure according to different cultural contexts. For example, they disclosed in the gay community but not in their ethnic community, or they disclosed when it affected only themselves but not when it affected their family.

PARTICIPANT: If it concerns privacy and it affects my family I keep it to myself, but if it doesn't affect my family then I will talk openly.

INTERPRETER: He also say that in that respect he thinks more like a Chinese. When he speaks openly, he's more like an Australian.

(Gay man from Hong Kong)

4 Support

For those whose immigration status was uncertain, support was limited and survival was precarious. New arrivals often had no one to turn to and were unfamiliar with HIV/AIDS service organisations. Some who managed to make contact with organisations were turned away because they were not eligible for assistance. Some had to work in physically demanding jobs to support themselves at a time when they were physically and emotionally very vulnerable.

PARTICIPANT: The first year I was isolated completely by depression. I didn't talk with anybody at all. I came only to ACON once, after the Multicultural HIV Service, and that was after almost one year or less, eight months.

INTERVIEWER: So, for eight months, what did you do?

PARTICIPANT: I stay alone a lot. It was very hard. I become very skinny. Living in different place. The kind of job I was doing was very hard, physical work.
(Colombian gay man)

Those who were eligible for services used social workers in clinics and mainstream HIV community organisations to help with practical problems (e.g. applying for benefits and housing) and one-on-one professional counselling.

Support groups run by mainstream HIV community organisations were not popular with participants in this study. Those who had never tried them, and who had no intention of doing so, were concerned about gossip and forced disclosure, which would also affect their families. Also, some were not familiar with the concept of group support and felt uncomfortable about discussing personal issues with strangers. Participants also had a utilitarian approach to support: problems needed to be solved, not just talked about. For those whose immigration status was precarious, the immigration problems weighed more heavily than their HIV problems.

'Talk to you is not much help. What they can do? We all know we got a problem but not the big solution.'
(Chinese gay man)

Some had tried support groups but found that they did not satisfy their needs. Asian gay men felt excluded and therefore uncomfortable in Caucasian groups.

'I went to the HIV [support group]. Yeah, but I feel that they are not for Asian type of people I think. They group each other and I don't feel comfortable at all ... I think they talk to each other. Australian they talk to each other ... Yeah, all Australian, only one Asian. So I feel isolated.'
(Thai gay man)

Some gay men also felt that there was too much talk about sex in support groups when participants needed help with survival. In addition, some participants did not see why they should associate with other positive people. It reminded them of their illness when they just wanted to get on with a normal life.

'So, I don't know why I need to go and talk with people who live with HIV the same as me. Better to meet with someone, you know, that talk with something else, have fun ... Yeah, going out together because they [friends] don't know what I have.'
(Thai heterosexual man)

It also reminded them that their health was likely to deteriorate:

CO-WORKER: With reference to people like her, ah, the one-to-one service is the best.

PARTICIPANT: ... not in group ... because many time people try to invite us: "Think about it." They invited us to the Blue Mountains and something like that. Is another group in [suburb]. [counsellor] is there. Ah, on Friday they share the lunch. She says, "There is computer for internet. There is massage if you want." Ah, we find people worse than us. I don't know ... Yeah, I don't know. We looking. We saw, is like they say, "Be careful!"

CO-WORKER: By the way they looked they conveyed the message "Be careful! This will happen to you. That's where you're heading." That's the message.
(Argentinian woman)

Those who attended support groups and found them useful stressed the importance of shared cultural values.

'[Culture is] very important because Asians are more conservative and not also as open as westerners. It relies on one Asian who looked for AIDS patients who sit together and in that case they are, the group, the people in the group will be more—will feel more easy ... Like, for instance, if there is a group of westerners and if you have another race—I should say race—or other people mixing in, they will not be as comfortable ... I don't know if you look at it—a group, if you are all Asian or got the same cultural background, you talk freely. There is no boundary in the culture. And in that case if they get it—people are from the same culture, get together, then they can talk more comfortably.'

(Gay man from Hong Kong)

It also seemed that the exchange of information on practical issues was more highly valued than talk about feelings.

'I get all my knowledge from there, information about medicine, treatment and nutrition. All these things I get from there. They get this from ACON and they learn all the first-hand information.' (*Gay man from Hong Kong*)

'It's more here in your head than in your body ... you can do many things with your mind. A lot. I think eighty per cent you can help yourself in that way. The rest, even the best medicine will not work.'

One common theme related to support was normality. Once participants had accepted HIV as a chronic condition, they were determined to get on with a normal life which included their usual social networks.

'I don't think about it—if I got HIV. I live like, you know, normal people ... I like to work, I like to meet friends. I like meeting up with friends. I have a cat. I like cleaning the house and I like looking after myself. ... chatting [with friends] about beauty [touching her face and hair], chatting about family (laughing).'

(*Thai woman*)

Regular contact with family and friends, both in Australia and in the country of birth, was important, no matter whether participants had disclosed their HIV status to them. Some participants received practical, financial and emotional support from family members who knew about their HIV status. However, family was also a source of

emotional support for those who had not disclosed their status.

'If I feel sad or upset I will call my mum, talk to my parents. I didn't talk about my ill ... just wanting to talk, hear their voice.'

(*Thai woman*)

Another common theme was self-reliance, or 'happiness from oneself'. Participants appreciated the support they got from family, friends and organisations, but they did not take it for granted. They helped themselves as much as they could but acknowledged that there were also areas of life where they could not help themselves

'It's more here in your head than in your body ... (not clear) ... not a cure but your mind, you can do many things with your mind. A lot. I think eighty per cent you can help yourself in that way. The rest, even the best medicine will not work.'

(*Colombian gay man*)

The preferred form of support to cover the gap that they could not fill themselves was one-on-one with someone from the same linguistic and cultural background. This ensured confidentiality and fitted in with participants' expectation of normality. Self-reliance also meant that participants utilised a range of resources unrelated to HIV. For some, it was spirituality, religion and the people of their congregation. For some, it was engaging with their young children. Some emphasised keeping busy and doing things for others.

One issue specific to women was domestic violence. The number of women in this study was small, but five of the seven women reported some form of abuse by their partners, including physical, verbal and social abuse. Only one participant mentioned seeking and receiving support for this.

Discussion

All participants had some knowledge about and experience with AIDS in their country of birth. However, very few were aware of the difference between HIV and AIDS. Participants had heard and read about AIDS, and some knew or had heard of people with AIDS in their country of birth. They knew that AIDS killed and that the social relations of people with AIDS and their local communities were disrupted.

Individuals balanced the public needs of social acceptance and normality against the private need of emotional support. They also balanced their own needs against the needs of significant others.

For all participants, HIV diagnosis was associated with death, irrespective of country of birth, level of education and year of diagnosis. In addition, for most participants, HIV was experienced as a cause of shame due to perceptions in ethnic communities related to homosexuality, injecting drug use, prostitution and, for women, having multiple sexual partners. Because of the strong interdependence of individuals with their families, an individual's HIV status brought shame on the whole extended family: parents, siblings, partners and children. This was aggravated by the misconception in ethnic communities that HIV could be transmitted through social contact. As a result, the HIV infection of an individual disrupted the social relations between the family and the local community. Some participants had actually experienced this in the country of birth. Therefore, they were highly selective about disclosure.

Disclosure was a multidimensional process balancing public and private needs. Individuals balanced the public needs of social acceptance and normality against the private need of emotional support. They also balanced their own needs against the needs of significant others. Protecting the family from shame and social stigma was vitally important.

Factors facilitating disclosure were closeness, trust, others' knowledge about HIV/AIDS and their ability to help. Participants saw no point disclosing to people who could not distinguish between HIV and AIDS. Furthermore, they saw no point in disclosing to people who were not able to help them.

People with HIV from CALD backgrounds are not passive victims but actively assess their social environment and decide whether or not to disclose according to this environment. They are creative and use cultural diversity to position themselves in a way that enables them to protect themselves and their families from stigma and prejudice and at the same time obtain the support they need to get on with their lives.

There are several implications for support. Firstly, confidentiality was of utmost importance. This was achieved through a minimalist approach to institutional support structures and a one-on-one relationship as the preferred model of support. Secondly, participants highlighted their self-reliance and drew on institutional support only for those aspects of their situation that they could not manage themselves. For some, their co-worker, a bilingual/bicultural support worker from the Multicultural HIV/AIDS and Hepatitis C Service, was the only person in their ethnic/cultural community who knew about their HIV status and in whom they confided. Thirdly, support in the mother tongue and shared cultural values were important. This form of support simultaneously represents closeness and distance: closeness through one-to-one support from the same cultural background and in the mother tongue; distance by virtue of being outside the participants' social network of family and friends. This enables people to talk about their concerns and at the same maintain silence about their HIV status among friends and family in both their country of birth and in Australia.

For all, some form of talk was important. However, for those whose immigration

status was uncertain, help with survival needs was even more important. Survival was threatened by two simultaneous processes: immigration and the demands of building a new life in a new country, and the need to rebuild life after an HIV diagnosis.

The process of immigration affected all aspects of living with HIV for virtually all participants, including those who were permanent residents. For some, it was the reason for an HIV test and a positive diagnosis. This, in turn, was

a barrier to permanent residency and participants had to go through a lengthy appeal process. The uncertainty of participants' residency status was an additional barrier to using health care and other services. For most participants, the mother tongue was important to make sense of the diagnosis, to learn about living with HIV and to receive ongoing support. A lack of English made it difficult for participants to make contact with service organisations. It also made it difficult to rebuild social relations in a new country without family and friends.

Conclusion

People with HIV from CALD backgrounds negotiate their lives within the historically and culturally constructed social relations of the communities in their country of birth, their ethnic communities in Australia and the Anglo-Celtic mainstream. They need to negotiate two major life disruptions: the disruption of immigration and the disruption of a chronic illness. They also need to negotiate two major uncertainties: the uncertainty of HIV and, in some cases, the uncertainty of their immigration status. Because of the association of HIV with shame

and because of the interdependence of individuals with their families, an individual's HIV diagnosis affects the whole extended family. Therefore, decisions about disclosure are made on the basis of interdependence between individuals, families and communities. If social relations are threatened by disclosure, disclosure is avoided. Therefore, people with HIV from CALD backgrounds need forms of support that are simultaneously outside the social networks of family and friends and inside the same language and culture.

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